DOCUMENT RESUME

ED 065 975 EC 042 888

TITLE	Mental Retardation and Other Developmental Disabilities, 1969.
INSTITUTION	Congress of the U.S., Washington, D.C. Senate Committee on Labor and Public Welfare.
REPORT NO	S-2846
PUB DATE	Nov 69
NOTE	469p.; Hearings before the Subcommittee on Health of the Committee on Labor and Public Welfare United States Senate Ninety-First Congress
AVAILABLE FROM	Superintendent of Documents, U. S. Government Printing Office, Washington, D. C. 20402
EDRS PRICE	MF-$0.65 HC-$16.45
DESCRIPTORS	Ancillary Services; *Exceptional Child Services; *Facilities; Federal Aid; Federal Government; *Federal Legislation; Government Role; *Mentally Handicapped; *National Programs

ABSTRACT

Congressional hearings on mental retardation and other developmental disabilities are presented for the stated purposes of assisting the states in developing a plan for the provision of comprehensive services to persons affected by mental retardation and other developmental disabilities originating in childhood, assisting the states in the provision of such services in accordance with such plan, assisting in the construction of facilities to provide the services needed to carry out such plan, and other purposes not enumerated. Included is a copy of S. 2846, the Developmental Disabilities Services and Facilities Construction Act of 1969. Mental retardation activities of the U. S. Department of Health, Education, and Welfare are summarized. Testimony of approximately 20 individuals for or against the legislation, focusing frequently on the financing of the federal program, constitutes the majority of the document. Reports of the President's Committee on Mental Retardation for 1968 abd 1969 are then included. Construction program of mental retardation research centers, university affiliated facilities, and community facilities throughout the country is provided. Concluding are copies of selected laws relating to mental retardation. (CB)

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MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES, 1969

HEARINGS

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON
LABOR AND PUBLIC WELFARE
UNITED STATES SENATE

NINETY-FIRST CONGRESS

FIRST SESSION

ON

S. 2846

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MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES, 1969

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ON

S. 2846

TO ASSIST THE STATES IN DEVELOPING A PLAN FOR THE PROVISION OF COMPREHENSIVE SERVICES TO PERSONS AFFECTED BY MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES ORIGINATING IN CHILDHOOD, TO ASSIST THE STATES IN THE PROVISION OF SUCH SERVICES IN ACCORDANCE WITH SUCH PLAN, TO ASSIST IN THE CONSTRUCTION OF FACILITIES TO PROVIDE THE SERVICES NEEDED TO CARRY OUT SUCH PLAN, AND FOR OTHER PURPOSES

NOVEMBER 10 AND 11, 1969

Printed for the use of the Committee on Labor and Public Welfare

U.S. GOVERNMENT PRINTING OFFICE
38-191 O WASHINGTON : 1969

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MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES, 1969

MONDAY, NOVEMBER 10, 1969

U.S. SENATE,
SUBCOMMITTEE ON HEALTH
OF THE COMMITTEE ON LABOR AND PUBLIC WELFARE,
Washington, D.C.

The subcommittee met at 9:30 a.m., pursuant to call, in room 4232, New Senate Office Building, Senator Edward M. Kennedy presiding pro tempore.

Present: Senators Kennedy (presiding pro tempore) and Dominick.

Committee staff members present: Robert O. Harris, staff director; James Babin, professional staff member to the subcommittee, and Jay B. Cutler, minority counsel to the subcommittee.

Senator KENNEDY. The subcommittee will come to order.

Today, the Senate Subcommittee on Health begins 2 days of public hearings on legislative proposals dealing with mental retardation and other developmental disabilities.

It has now been 6 years since Congress enacted the basic Federal legislation in this area. We know from the rising level of public concern over this major national problem that the scope and funding of our present efforts are far too narrow to provide the services and facilities that are needed.

In the course of these hearings, the subcommittee will receive testimony from public officials, private citizens and the representatives of a number of organizations and institutions familiar with the needs and aspirations of the retarded.

The legislation pending before the subcommittee is S. 2846, the "Developmental Disabilities Services and Facilities Construction Act of 1969," which I introduced in the Senate in August, and which is cosponsored by Senators Yarborough, Williams of New Jersey, Nelson, Mondale, Eagleton, Cranston, Hart, and Javits.

The text of the bill, along with my remarks at the time I introduced it, shall be printed at this point.

(The bill S. 2846 and introductory remarks follow:)

7

91st CONGRESS
1st Session

S. 2846

IN THE SENATE OF THE UNITED STATES

August 13, 1969

Mr. Kennedy (for himself, Mr. Yarborough, Mr. Cranston, Mr. Eagleton, Mr. Hart, Mr. Javits, Mr. Mondale, Mr. Nelson, and Mr. Williams of New Jersey) introduced the following bill; which was read twice and referred to the Committee on Labor and Public Welfare

---

A BILL

To assist the States in developing a plan for the provision of comprehensive services to persons affected by mental retardation and other developmental disabilities originating in childhood, to assist the States in the provision of such services in accordance with such plan, to assist in the construction of facilities to provide the services needed to carry out such plan, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SHORT TITLE

Section 1. This Act may be cited as the "Developmental Disabilities Services and Facilities Construction Act of 1969."

II

TITLE I—GRANTS FOR PLANNING, PROVISION OF SERVICES, AND CONSTRUCTION OF FACILITIES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

SEC. 101. Part C of the Mental Retardation Facilities Construction Act, as amended, is amended by striking out sections 131 through 137 and substituting the following:

"PART C—GRANTS FOR PLANNING, PROVISION OF SERVICES, AND CONSTRUCTION OF FACILITIES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

"DECLARATION OF PURPOSE

"SEC. 130. The purpose of this part is—

"(a) to make grants to assist the several States in developing and implementing a comprehensive and continuing plan for meeting the current and future needs for services to persons affected by developmental disabilities; and

"(b) to make grants to assist public and nonprofit agencies in the construction of facilities for the provision of services to persons affected by developmental disabilities.

"AUTHORIZATION OF APPROPRIATIONS

"SEC. 131. In order to make the grants to carry out the provisions of section 130, there are authorized to be appropriated $100,000,000 for the fiscal year ending June 30, 1971, $150,000,000 for the fiscal year ending June 30, 1972, $200,000,000 for the fiscal year ending June 30, 1973, $250,000,000 for the fiscal year ending June 30, 1974, and $250,000,000 for the fiscal year ending June 30, 1975.

“STATE ALLOTMENTS

“SEC. 132. (a) (1) From the sums appropriated to carry out the purposes of section 130 for each fiscal year, the several States shall be entitled to allotments determined, in accordance with regulations, on the basis of (A) the population, (B) the extent of need for services and facilities for persons with developmental disabilities, and (C) the financial need of the respective States; except that the allotment of any State (other than the Virgin Islands, American Samoa, Guam, and the Trust Territory of the Pacific Islands) for any such fiscal year shall not be less than $100,000.

“(2) In determining, for purposes of paragraph (1), the extent of need in any State for services and facilities for persons with developmental disabilities, the Secretary shall take into account the scope and extent of the services specified, pursuant to section 134 (b) (4), in the State plan of such State approved under this part.

“(3) Sums allotted to a State for a fiscal year and designated by it for construction and remaining unobligated at the end of such year shall remain available to such State for such purpose for the next fiscal year (and for such year only), in addition to the sums allotted to such State for such next fiscal year: *Provided,* That whenever the State plan calls for the construction of a specific facility the Federal share of which will exceed the State's maximum permissible allotment for construction for the fiscal year, the Secretary may, on the request of the State, provide that funds allotted to the State remain available, to the extent necessary but not to exceed two additional years, to be combined with subsequent allotments for the specified purpose.

"(b) Whenever the State plan developed in accordance with section 134 provides for participation of more than one State agency in administering or supervising the administration of designated portions of the State plan, the State may apportion its allotment among such agencies in a manner which, to the satisfaction of the Secretary, is reasonably related to the responsibilities assigned to such agencies in carrying out the purposes of this part. Funds so apportioned to State agencies may be combined with other State or Federal funds authorized to be spent for other purposes, provided the purposes of this part will receive proportionate benefit from the combination.

"(c) The amount of an allotment to a State for a fiscal year which the Secretary determines will not be required by the State during the period for which it is available for the purpose for which allotted shall be available for reallotment by the Secretary from time to time, on such date or dates as he may fix, to other States with respect to which such a determination has not been made, in proportion to the original allotments of such States for such fiscal year, but with such proportionate amount for any of such other States being reduced to the extent it exceeds the sum the Secretary estimates such State needs and will be able to use during such period; and the total of such reductions shall be similarly reallotted among the States whose proportionate amounts were not so reduced. Any amount so reallotted to a State for a fiscal year shall be deemed to be a part of its allotment under subsection (a) for such fiscal year.

"NATIONAL ADVISORY COUNCIL ON SERVICES AND FACILITIES FOR THE DEVELOPMENTALLY DISABLED

"SEC. 133. (a) (1) There is hereby established a National Advisory Council on Services and Facilities for the Developmentally Disabled (hereinafter referred to as the 'Council'), which shall consist of twelve members, not otherwise in the regular full-time employ of the United States, to be appointed by the Secretary without regard to the provisions of title 5, United States Code, governing appointments in the competitive civil service.

"(2) The Secretary shall from time to time designate one of the members of the Council to serve as Chairman thereof.

"(3) The members of the Council shall be selected from leaders in the fields of service to the mentally retarded and other developmentally disabled persons, in State or local government, and in organizations representing consumers of such services. At least four members shall be representative of State or local agencies responsible for services to the developmentally disabled, and at least four shall be representative of the interests of consumers of such services.

"(b) Each member of the Council shall hold office for a term of four years, except that any member appointed to fill a vacancy occurring prior to the expiration of the term for which his predecessor was appointed shall be appointed for the remainder of such term, and except that, of the twelve members first appointed, three shall hold office for a term of three years, three shall hold office for a term of two years, and three shall hold office for a term of one year, as designated by the Secretary at the time of appointment.

"(c) It shall be the duty and function of the Council to (1) advise the Secretary with respect to any regulations promulgated or proposed to be promulgated by him in the implementation of this title, and (2) study and evaluate programs authorized by this title with a view to determining their effectiveness in carrying out the purposes for which they were established.

"(d) The Council is authorized to engage such technical assistance as may be required to carry out its functions, and the Secretary shall, in addition, make available to the Council such secretarial, clerical, and other assistance and such statistical and other pertinent data prepared by or available to the Department of Health, Education, and Welfare as it may require to carry out such functions.

"(e) Members of the Council, while attending meetings or conferences thereof or otherwise serving on the business of the Council, shall be entitled to receive compensation at rates fixed by the Secretary, but not exceeding $100 per day and, while so serving away from their homes or regular places of business, they may be allowed travel expenses, including per diem in lieu of subsistence, as authorized by section 5703 of title 5, United States Code, for persons in the Government service employed intermittently.

"STATE PLANS

"SEC. 134. (a) Any State desiring to take advantage of this part must have a State plan submitted to and approved by the Secretary under this section.

"(b) In order to be approved by the Secretary under this section, a State plan for the provision of services and facilities for persons with developmental disabilities must—

"(1) designate (A) a State planning and advisory council, to be responsible for submitting revisions of the State plan and transmitting such reports as may be required by the Secretary; (B) the State agency or agencies which may administer or supervise the administration of all or designated portions of the State plan; and (C) a single State agency as the sole agency for administering or supervising the administration of grants for construction under the State plan;

"(2) set forth policies and procedures for the expenditure of funds under the plan, which, in the judgment of the Secretary, are designed to assure effective continuing State planning, evaluation, and delivery of services (both public and private) for persons with developmental disabilities;

"(3) contain or be supported by assurances satisfactory to the Secretary that (i) the funds paid to the State under this part will be used to make a significant contribution toward strengthening services for persons with developmental disabilities in the various political subdivisions of the State in order to improve the quality, scope, and extent of such services; (ii) part of such funds will be made available to other public or nonprofit private agencies, institutions, and organizations; (iii) such funds will be used to supplement and, to the extent practicable, to increase the level of funds that would otherwise be made available for the purposes for which the Federal funds are provided and not to supplant such non-Federal funds; and (iv) there will be reasonable State financial participation in the cost of administering and implementing the State plan;

"(4) (A) provide for the furnishing of a range of services and facilities for persons with developmental disabilities associated with mental retardation, (B) specify the other categories of developmental disabilities which will be included in the State plan, and (C) describe the quality, extent and scope of such services as will be provided to persons with mental retardation and other developmental disabilities;

"(5) provide that services and facilities furnished under the plan for persons with developmental disabilities will be in accordance with standards prescribed by regulations, including standards as to the scope and quality of such services and the maintenance and operation of such facilities;

"(6) provide such methods of administration (including methods relating to the establishment and maintenance of personnel standards on a merit basis, except that the Secretary shall exercise no authority with respect to the selection, tenure of office, and compensation of any individual employed in accordance with such methods) as are found by the Secretary to be necessary for the proper and efficient operation of the plan;

"(7) provide that the State planning and advisory council shall be adequately staffed, shall include representatives of each of the principal State agencies and representatives of local agencies and nongovernmental organizations and groups concerned with services for persons with developmental disabilities: *Provided*, That at least one-third of the membership of such council shall consist of representatives of consumers of such services;

"(8) provide that the State planning and advisory council will from time to time, but not less often than annually, review and evaluate its State plan approved under this section and submit appropriate modifications to the Secretary;

"(9) provide that the State agencies designated in paragraph (1) will make such reports, in such form and containing such information, as the Secretary may from time to time reasonably require, and will keep such records and afford such access thereto as the Secretary finds necessary to assure the correctness and verification of such reports;

"(10) provide that special financial and technical assistance shall be given to areas of urban or rural poverty in securing services and facilities for developmentally disabled residents of such areas;

"(11) describe the methods to be used to assess the effectiveness and accomplishments of the State in meeting the needs of developmentally disabled persons in the State;

"(12) provide for the development of a program of construction of facilities for the provision of services for persons with developmental disabilities which (A) is based on a statewide inventory of existing facilities and survey of need; and (B) which meets the requirements prescribed by the Secretary for furnishing needed services to persons unable to pay therefor;

"(13) set forth the relative need, determined in accordance with regulations prescribed by the Secretary, for the several projects included in the construction program referred to in paragraph (12), and assign priority to the construction of projects, insofar as financial resources available therefor and for maintenance and operation make possible, in the order of such relative need;

"(14) specify the per centum of the State's allotment (under section 132) for any year which is to be devoted to construction of facilities, which per centum shall be not more than 50 per centum or such lesser per centum of the allotment as the Secretary may from time to time prescribe;

"(15) provide for affording to every applicant for a construction project an opportunity for hearing before the State agency;

"(16) provide for such fiscal control and fund accounting procedures as may be necessary to assure the proper disbursement of and accounting for funds paid to the State under this part; and

"(17) contain such additional information and assurances as the Secretary may find necessary to carry out the provisions and purposes of this part.

"(c) The Secretary shall approve any State plan and any modification thereof which complies with the provisions of subsection (b). The Secretary shall not finally disapprove a State plan except after reasonable notice and opportunity for a hearing to the State.

"APPROVAL OF PROJECTS FOR CONSTRUCTION

"SEC. 135. (a) For each project for construction pursuant to a State plan approved under this part, there shall be submitted to the Secretary, through the State agency designated in section 134 (b) (1) (C), an application by the State or a political subdivision thereof or by a public or other nonprofit agency. If two or more agencies join in the construction of the project, the application may be filed by one or more of such agencies. Such application shall set forth—

"(1) a description of the site for such project;

"(2) plans and specifications thereof, in accordance with regulations prescribed by the Secretary;

"(3) reasonable assurance that title to such site is or will be vested in one or more of the agencies filing the application or in a public or other nonprofit agency which is to operate the facility;

"(4) reasonable assurance that adequate financial support will be available for the construction of the project and for its maintenance and operation when completed;

"(5) reasonable assurance that all laborers and mechanics employed by contractors or subcontractors in the performance of work on construction of the project will be paid wages at rates not less than those prevailing on similar construction in the locality as determined by the Secretary of Labor in accordance with the Davis-Bacon Act, as amended (40 U.S.C. 276a—276a-5); and the Secretary of Labor shall have with respect to the labor standards specified in this paragraph the authority and functions set forth in Reorganization Plan Numbered 14 of 1950 (15 F.R. 3176) and section 2 of the Act of June 13, 1934, as amended (40 U.S.C. 276c); and

"(6) a certification by the State agency of the Federal share for the project.

"(b) The Secretary shall approve such application if sufficient funds to pay the Federal share of the cost of construction of such project are available from the allotment to the State, and if the Secretary finds (1) that the application contains such reasonable assurances as to title, financial support, and payment of prevailing rates of wages and overtime pay, (2) that the plans and specifications are in accord with regulations prescribed by the Secretary, (3) that the application is in conformity with the State plan approved under this part, and (4) that the application has been approved and recommended by the State agency and is entitled to priority over other projects within the State in accordance with the State's plan for persons with developmental disabilities and in accordance with regulations prescribed by the Secretary.

"(c) No application shall be disapproved until the Secretary has afforded the State agency an opportunity for a hearing.

"(d) Amendment of any approved application shall be subject to approval in the same manner as the original application.

"WITHHOLDING OF PAYMENTS FOR CONSTRUCTION

"SEC. 136. Whenever the Secretary, after reasonable notice and opportunity for hearing to the State agency designated in section 134 (b) (1) (C) finds—

"(a) that the State agency is not complying substantially with the provisions required by section 134 (b) to be included in the State plan, or with regulations of the Secretary;

"(b) that any assurance required to be given in an application filed under section 135 is not being or cannot be carried out;

"(c) that there is a substantial failure to carry out plans and specifications related to construction approved by the Secretary under section 134; or

"(d) that adequate funds are not being provided annually for the direct administration of the State plan,

the Secretary may forthwith notify the State agency that—

"(e) no further payments will be made to the State for construction from allotments under this part; or

"(f) no further payments will be made from allotments under this part for any project or projects designated by the Secretary as being affected by the action or inaction referred to in paragraph (a), (b), (c), or (d) of this section;

as the Secretary may determine to be appropriate under the circumstances; and, except with regard to any project for which the application has already been approved and which is not directly affected, further payments for construction projects may be withheld, in whole or in part, until there is no longer any failure to comply (or to carry out the assurance or plans and specifications or to provide adequate funds, as the case may be) or, if such compliance (or other action) is impossible, until the State repays or arranges for the repayment of Federal moneys to which the recipient was not entitled.

"PAYMENTS TO THE STATES FOR PLANNING AND SERVICES

"SEC. 137. (a) (1) From each State's allotments for a fiscal year under section 132, the State shall be paid the Federal share of the expenditures, other than expenditures for construction, incurred during such year under its State plan approved under this part. Such payments shall be made from time to time in advance on the basis of estimates by the Secretary of the sums the State will expend under the State plan, except that such adjustments as may be necessary shall be made on account of previously made underpayments or overpayments under this section.

"(2) For the purpose of determining the Federal share of any State, expenditures by a political subdivision thereof or by nonprofit private agencies, organizations, and groups shall, subject to such limitations and conditions as may be prescribed by regulations, be regarded as expenditures by such State.

"(b) The 'Federal share' for any State for purposes of this section for any fiscal year shall be 80 per centum of the expenditures, other than expenditures for construction, incurred by the State during such year under its State plan approved under this part.

"WITHHOLDING OF PAYMENTS FOR PLANNING AND SERVICE

"SEC. 138. Whenever the Secretary, after reasonable notice and opportunity for hearing to the State planning and advisory council finds that—

"(1) there is a failure to comply substantially with any of the provisions required by section 134 to be included in the State plan; or

"(2) there is a failure to comply substantially with any regulations of the Secretary which are applicable to this part,

the Secretary shall notify such State council that further payments will not be made to the State under this part (or, in his discretion, that further payments will not be made to the

State under this part for activities in which there is such failure), until he is satisfied that there will no longer be such failure. Until he is so satisfied, the Secretary shall make no further payment to the State under this part, or shall limit further payment under this part to such State to activities in which there is no such failure.

"REGULATIONS

"SEC. 139. Not later than March 1, 1970, the Secretary, after consultation with the National Advisory Council on Services and Facilities for the Developmentally Disabled (established by section 133), by general regulations applicable uniformly to all the States, shall prescribe—

"(1) the kinds of services which are needed to provide adequate programs for persons with developmental disabilities, the kinds of services which may be provided under this part, and the categories of persons for whom such services may be provided;

"(2) standards as to the scope and quality of services which must be provided for persons with developmental disabilities under a State plan approved under this part;

"(3) the general manner in which a State, in carrying out its State plan approved under this part, shall determine priorities for services and facilities based on type of service, categories of persons to be served, and type of disability, with special consideration being given to the needs for such services and facilities in areas of urban and rural poverty; and

"(4) general standards of construction and equipment for facilities of different classes and in different types of location.

"NONDUPLICATION

"SEC. 140. (a) In determining the amount of any payment for the construction of any facility under a State plan approved under this part, there shall be disregarded (1) any portion of the costs of such construction which are financed by Federal funds provided under any provision of law other than this part, and (2) the amount of any non-Federal funds required to be expended as a condition of receipt of such Federal funds.

"(b) In determining the amount of any State's Federal share of expenditures for planning and services incurred by it under a State plan approved under this part, there shall be disregarded (1) any portion of such expenditures which are financed by Federal funds provided under any provision of law other than this part, and (2) the amount of any non-Federal funds required to be expended as a condition of receipt of such Federal funds."

SEC. 102. (a) Section 401 of the Mental Retardation

Facilities and Community Mental Health Centers Construction Act of 1963, as amended (42 U.S.C. 2691), is amended by—

(1) inserting "the Trust Territory of the Pacific Islands" after "American Samoa" in subsection (a);

(2) striking out subsection (b) and inserting in lieu thereof the following:

"(2) The term 'facility for the developmentally disabled' means a facility, or a specified portion of a facility, designed primarily for the delivery of one or more services to persons affected by one or more developmental disabilities.";

(3) striking out the words "mentally retarded" wherever they occur in subsection (d) and inserting the words "developmentally disabled" in lieu thereof;

(4) striking out "August 31" in subsection (j) (1) and inserting in lieu thereof "September 30"; and

(5) by adding at the end of the section the following subsections:

"(l) The term 'developmental disability' means a disability attributable to mental retardation, cerebral palsy, epilepsy, a neurological impairment, a sensory defect, or any other chronic physical or mental impairment of an individual which originates before such individual attains age eighteen, which has continued or can be expected to continue indefinitely, and which constitutes a substantial handicap to such individual.

"(m) The term 'services for persons with developmental disabilities' means specialized services or special adaptations of generic services directed toward the alleviation of a developmental disability or toward the social, personal, physical, or economic habilitation or rehabilitation of an individual affected by such a disability, and such term includes diagnosis, evaluation, treatment, personal care, day-care, domiciliary care, special living arrangements, training, education, sheltered employment, recreation, counseling of the individual affected by such disability and of his family, protective and other social and socio-legal services and information and referral services.

"(n) The term 'regulations' means (unless the text otherwise indicates) regulations promulgated by the Secretary."

(b) Sections 403 and 405 of such Act are amended by inserting the words "or the developmentally disabled" after the words "mentally retarded" wherever they occur.

EFFECTIVE DATE

SEC. 103. The amendments made by this title shall apply with respect to fiscal years beginning after June 30, 1970: *Provided, however,* That funds appropriated prior to that date under part C of the Mental Retardation Facilities

Construction Act shall remain available for obligation during the fiscal year ending June 30, 1971.

TITLE II—AMENDMENTS TO PART B OF THE MENTAL RETARDATION FACILITIES CONSTRUCTION ACT

CAPTION

SEC. 201. (a) (1) The caption to part B of the Mental Retardation Facilities Construction Act is amended to read as follows:

"CONSTRUCTION, DEMONSTRATION AND TRAINING GRANTS FOR UNIVERSITY-AFFILIATED MENTAL RETARDATION FACILITIES".

CONSTRUCTION GRANTS

SEC. 202. (a) The first sentence of section 121(a) of the Mental Retardation Facilities Construction Act is amended—

(1) by striking out "clinical facilities providing, as nearly as practicable, a full range of inpatient and outpatient services for the mentally retarded (which for purposes of this part, includes other neurological handicapping conditions found by the Secretary to be sufficiently related to mental retardation to warrant inclusion in this part) and";

(2) by striking out "clinical training" and inserting in lieu thereof: "interdisciplinary training"; and

(3) by striking out "each for the fiscal year ending June 30, 1969, and the fiscal year ending June 30, 1970" and inserting in lieu thereof: "for each of the next seven fiscal years".

(b) Section 121 of such Act is amended by adding at the end thereof the following subsection:

"(c) For purposes of this part, the term 'mentally retarded' shall include mental retardation and other neurological handicapping conditions found by the Secretary to be sufficiently related to mental retardation to warrant inclusion in this part."

DEMONSTRATION AND TRAINING GRANTS

SEC. 203. Part B of the Mental Retardation Facilities Construction Act is amended by redesignating sections 122, 123, 124, and 125 as sections 123, 124, 125, and 126, respectively, and by adding the following new section after section 121:

"SEC. 122. (a) For the purpose of assisting institutions of higher education to contribute more effectively to the solution of complex health, education, and social problems of children and adults suffering from mental retardation, the Secretary may, in accordance with the provisions of this part, make grants to cover costs of administering and operating demonstration facilities and interdisciplinary training programs for personnel needed to render specialized services to the mentally retarded, including established disciplines as well as new kinds of training to meet critical shortages in the care of the mentally retarded.

"(b) For the purpose of making grants under this section, there is authorized to be appropriated $7,000,000 for the fiscal year ending June 30, 1971; $11,000,000 for the fiscal year ending June 30, 1972; $15,000,000 for the fiscal year ending June 30, 1973; and $20,000,000 for each of the next two fiscal years.

Sec. 204. Section 123 of such Act, as redesignated by this Act is, amended by inserting "(a)" after "Sec. 122," by inserting "the construction of" before "any facility," and by adding the following new subsection at the end thereof:

"(b) Applications for demonstration or training grants under this part may be approved by the Secretary only if the applicant is a college or university operating a facility of the type described in section 121, or is a public nonprofit agency or organization operating such a facility."

Sec. 205. Section 124 of such Act, as redesignated by this Act, is amended by deleting the phrases "for the construction of a facility" and "of construction" in subsection (a) thereof, and by deleting the phrase "in such installments consistent with construction progress,".

Sec. 306. Section 125 of such Act, as redesignated by this Act, is amended by inserting "construction" before "funds" in the first line thereof.

MAINTENANCE OF EFFORT

SEC. 307. Such Act is amended by adding at the end thereof the following new section:

"SEC. 126. Applications for grants under this part may be approved by the Secretary only if the application contains or is supported by reasonable assurances that the grants will not result in any decrease in the level of State, local, and other non-Federal funds for mental retardation services and training which would (except for such grant) be available to the applicant, but that such grants will be used to supplement, and, to the extent practicable, to increase the level of such funds."

S. 2846—INTRODUCTION OF A BILL TO PROVIDE SERVICES AND FACILITIES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

Mr. KENNEDY. Mr. President, on behalf of Senator Yarborough and myself, I introduce for appropriate reference the Developmental Disabilities Services and Facilities Construction Act of 1969. The principal title of the bill would broaden existing Federal grant programs by providing an extensive new range of services and facilities for the mentally retarded and other persons affected by developmental disabilities. A separate title of the bill would extend for 5 years the current statutory program authorizing construction of university facilities and training programs for the care and treatment of the developmentally disabled, and would amend the existing legislation to place greater emphasis on the interdisciplinary character of such programs.

In 1963 Congress enacted the first major Federal legislation for the specific assistance of the mentally retarded. The Mental Retardation Facilities Construction Act, enacted as part of the combined mental health-mental retardation legislation of that year, was the outgrowth of the pathbreaking work of the President's Panel on Mental Retardation, appointed by President Kennedy in 1962.

The President's Panel found an appalling shortage of appropriate residential and nonresidential facilities for our mentally retarded citizens, both children and adults. The panel also recognized the need for new approaches to the training of personnel to work with the handicapped, to diagnose their difficulties, to treat their disorders, to train their crippled minds, to cultivate their potential for rewarding activity, and to counsel their bewildered families.

The Panel also recognized the need for the establishment of special centers for research into the causes of mental retardation and its care and treatment. In such centers, the differing skills of a variety of professionals and other research experts could be focused on the basic unknowns of mental retardation, such as the chromosome abnormality in mongolism, or the effect of malnutrition on the prenatal development of infants.

The investigators would study new methods for teaching language to children who do not learn to speak in the normal way. They would develop improved methods of behavioral training to overcome many of the other obstacles that block the progress of retarded children, and better ways to train groups of children in residential and nonresidential facilities.

In the Mental Retardation Facilities Construction Act of 1963, Congress implemented many of the panel's basic recommendations. In the various provisions of the act, Congress established a program of Federal financial assistance for the construction of three types of facilities for the mentally retarded:

Community facilities for the retarded;

University-affiliated clinical facilities for the diagnosis, care, treatment, and training of the retarded, in conjunction with programs to train professional personnel to help such persons; and

Centers for research on mental retardation and related aspects of human development.

In the initial years under the 1963 act, Congress gave enthusiastic support to these three complementary programs. However, after a dozen mental retardation research centers had been funded, the construction authority for this program was allowed to lapse. The authorization for the so-called university-affiliated facility program was renewed in 1967, but the program has been underfunded since that time. In addition, budgetary restrictions have also forced a serious curtailment of the Community Facility Program in recent years.

At the same time, however, there were liberalizing influences. In late 1967, in response to the need for assistance in staffing the community facilities, Congress amended the legislation to authorize grants to be made for such staffing. The first staffing grants under this amendment were announced last month, July 1969. Nearly 300 applications, requesting Federal funds totaling over $14 million for the first full year of operation, were received, even though only $8 million was actually appropriated for the fiscal year 1969.

At the present time, under the 1963 act as it has been amended, approximately 300 community facilities and 1[illegible] facilities for university training programs have been funded. For the construction of facilities for the retarded, Congress has obligated a total of $56 million over a period of 5 fiscal years. Ironically, this amount is only slightly higher than the amount recommended by the President's Panel for each of the first 10 years of the proposed program. And, it represents less than one-third of the total cost of the facilities that have been established.

We know that the scope and current level of funding of these programs are too narrow to meet the constantly increasing demand for services and facilities for the retarded in all parts of the Nation. That demand represents the conscientious response in each of the 50 States by concerned citizens eager to right the wrongs and injustices suffered by this long-neglected segment of our population.

The work that Congress began so well in 1963 is far from finished. Each of the present grant programs in this crucial area will expire in less than a year. Yet, even now, responsible State agencies estimate that projects requiring an additional $100 million in Federal funds are on the drawing boards awaiting the availability of Federal funds. The time is long past due for action by Congress to expand and extend this vital legislation.

In its recent report entitled "MR 1968," the President's Committee on Mental Retardation highlighted many of the current problems of inadequate care and treatment for the retarded. One of the most serious problems documented by the Committee concerns the lack of satisfactory residential care facilities for the retarded. At least 50 percent of the country's institutionalized retarded live in functionally inadequate buildings whose average age is 44 years. The staffs are overworked, underpaid, and ineffectively used. Many of the staff personnel are poorly trained. Waiting lists for the admission of the retarded—both children and adults—are far too long.

To a limited extent, other Federal programs have helped to fill the gap. Small islands of innovation have been created under the so-called HIP and HIST programs—the hospital improvement program and the hospital inservice training program. These two programs are operated on a project grant basis. For the past 3 years, however, less than $9 million has been appropriated annually for these programs, and scarcely more than half of the 170 public institutions for the retarded in the country have been able to benefit from them.

The President's Committee recommended that substantial Federal funds should be made available to all public institutions for the retarded. Grants would be made on the basis of a comprehensive State plan. Under the plan, existing institutions would be required to meet specified standards, and new types of localized residential facilities would be developed. Such facilities would not have the dehumanizing characteristics often associated with large remote hospitals. Under the Committee's recommendation, the Federal program could move from an underfunded project approach to a more realistic grant approach that would include a direct attack on the problem of inadequate residential care.

It is widely recognized today that mental retardation is often associated with other kinds of developmental disabilities—such as cerebral palsy, epilepsy, congenital malformations, sensory disorders, and the like. Moreover, even normally intelligent children and adults with such developmental disorders may have problems requiring special care, training, treatment, and living arrangements similar to those needed by the mentally retarded. Yet, unlike the retarded, they frequently have urgent needs which are not covered by any of our existing Federal grant programs. I believe that our programs should be expanded to cover these persons as well.

Another significant problem in the care and treatment of the retarded under existing Federal legislation concerns the anomalous position of mental retardation in the Partnership for Health Act, which was enacted by Congress in 1966. Under that act, the Public Health Service has begun to move away from the so-called categorical grant approach to health services. As an inadvertent result of this approach, however, there has been a serious decline in the overall Federal and State commitments in the area of mental retardation.

In the Partnership for Health Act, Congress recognized that, more often than not, State health departments do not have the primary responsibility for mental health. Therefore, Congress sought to protect the existing programs for mental health services and facilities. It required that at least 15 percent of the basic formula grant to each State for health services must be placed at the disposal of the State mental health authorities.

No such provision was made applicable, however, in the case of funds for mental retardation. Congress failed to recognize that, just as in the case of mental health, facilities and services for the mentally retarded are often the responsibility of other State agencies, and are often not exclusively or even primarily the responsibility of State health departments. Even in the States which include mental retardation within the scope of their mental health agencies, here is no assurance that the mentally retarded will receive their proportionate share of the benefits of the Partnership for Health Act. Thus, the mentally retarded still do not have the benefit of the kind of impetus that Congress has given to the States with respect to many other health and mental health-related problems.

It is time to remedy this oversight by providing specific Federal financial assistance to the States for a wide variety of mental retardation services and facilities. In addition, broad flexibility should be allowed each State to apportion its mental retardation grants among its various governmental agencies, in accordance with the particular State plan, and to include persons with related disorders.

The magnitude of the problem of mental retardation was already enormous in 1963, the year the basic Federal statute was enacted. Since that time, officials and responsible citizens have become even more acutely aware of the extent of the problem. The comprehensive State planning effort undertaken with Federal support and encouragement during the years 1965 through 1968 has pinpointed many of the defects in the present system. Each State now has a view of its problems and its priorities, and of the steps it must take to meet them. In many States, new agencies have been created to spearhead the effort and bring a more effective and diversified attack on the problem.

Yet another aspect of the problem of mental retardation involves the need for better training of professional personnel working in this area. In 1962, few physicians, psychologists, social workers, rehabilitation counselors, physical therapists, and others who could have contributed to the rehabilitation of the mentally retarded had the opportunity during their training for firsthand contact with handicapped children and adults. Even fewer had the opportunity to observe or participate in demonstration programs for the education, care, or treatment of such persons.

Part B of the Mental Retardation Facilities Construction Act of 1963 was addressed to this serious deficiency. It authorized Federal grants for the construction of clinical and demonstration facilities affiliated with colleges or universities. A major emphasis of such grants was on the use of the facilities for training physicians and other specialized personnel. Although the first facilities funded under this program have now become operational, it will be several years before the specialists trained in the facilities will begin to have a significant impact on services for the retarded.

In the course of developing the plans for these facilities—of which 18 have now been approved and funded under the act—important lessons have been learned. It has become especially clear that the proper approach to mental retardation, like many of today's complex problems, requires the application of a variety of skills exercised in concert. Professional training of people to attack this problem must include not only skills traditional to their respective disciplines, but also techniques of professional teamwork and cooperative action by persons of diverse training and background.

In addition, there is an urgent need for training new kinds of personnel to meet the critical shortage in our existing system of care for the mentally retarded. We must encourage the development of new types of professionals and subprofessionals, who may be able to provide even better services for the retarded in many respects than the presently established disciplines are able to provide.

For all of the reasons I have mentioned, the time has come to create new and more comprehensive approaches to the problems we first began to attack in the 1963 legislation. Some of these approaches are proposed in the Developmental Disabilities Services and Facilities Construction Act of 1969, which I am introducing today.

In essence, the bill would assist the States in planning and carrying out a comprehensive program of facilities and services for persons suffering from mental retardation or other serious chronic mental or physical disabilities originating in childhood. Such disabilities are referred to in the Act as "developmental disabilities." The bill would provide broad grants for the establishment, extension, improvement, and supplementary support of services, facilities, and training needed for the care and treatment of persons with such disabilities.

In particular, title I of the bill would:

Assist the States in preparing and implementing comprehensive plans for the care and treatment of persons suffering from mental retardation or a broad range of other developmental disabilities;

Provide resources for improving residential care for the retarded, as recommended by the President's Committee on Mental Retardation;

Permit States to apportion parts of their grants among several State agencies, which may share the responsibility for implementing the State plan;

Permit State agencies to combine grant funds with other program funds, where proportionate benefit to the developmentally disabled will result; and

Permit the States to adopt a wide variety of modes of funding their projects, including grants to voluntary organizations and universities.

This portion of the bill would authorize appropriations of $100 million for fiscal year 1971, $150 million for fiscal year 1972, $200 million for fiscal year 1973, $250 million for fiscal year 1974 and $250 million for fiscal year 1975.

Title II of the bill would extend for 5 years—with annual authorizations at the present level of $20 million per year—the authority for Federal grants for construction of university-affiliated facilities for the mentally retarded and persons with related neurological handicaps. Such facilities would be established in conjunction with programs for the training of personnel for the diagnosis, education, care, training, and treatment of personnel for the diagnosis, education, care, training, and treatment of the retarded. The bill would further modify the existing law by placing greater emphasis on the interdisciplinary character of these training programs.

In addition, title II provides that grants for such facilities may be used to pay part of the basic costs of administering and operating the facilities. If Federal support for these basic costs can be reliably assured, the facilities will be able to attract better support from the communities and the State agencies they serve, as well as from Federal agencies with established responsibilites for professional manpower development in related disciplines. Title II authorizes the appropriation of a total of $73 million for this purpose over a 5-year period.

I am hopeful that the proposed legislation will give us new determination to attack the problems of the mentally retarded and those with other developmental disabilities. For too long, we have been content with inadequate guestures in this vital field. I look forward to the coming hearings and debates on this and other legislation as a fresh opportunity for us in Congress to examine our present efforts and establish creative new programs for the future.

Senator **Kennedy**. At the outset, let me say that I appreciate the assistance and cooperation of Senator Yarborough, the distinguished chairman of this subcommittee, in allowing me to go forward with the preparation of these hearings during his official absence from the Senate on an important international mission.

Senator Yarborough and I, along with each of the other members of this subcommittee, share a strong and deep commitment to the cause of providing a better life for those afflicted with mental retardation and other developmental disabilities.

We look forward to these hearings as a major step toward establishing a more effective Federal program for the future.

At this point, I would like to include as part of the record an opening statement prepared by Senator Yarborough for these hearings.

PREPARED STATEMENT OF HON. RALPH YARBOROUGH, A U.S. SENATOR FROM THE STATE OF TEXAS

In 1963 the Congress passed the Mental Retardation Facilities Construction Act, as part I of a combined mental health-mental retardation bill—Public Law 88-164. Although the two parts of this bill were somewhat similar in format, their origins were quite differnt. The mental retardation portion was the direct result of the work of the President's Panel on Mental Retardation, appointed by President Kennedy in 1962.

This body found an appalling shortage of appropriate residential and nonresidential facilities for the mentally retarded, both children and adults. It also saw the need for new approaches to training personnel to work with these handicapped people, to diagnose their difficulties, treat their disorders, train their crippled minds, cultivate their potentials for rewarding activity, and counsel their bewildered families. To make the work of the professionals more effective, the President's Panel also recommended the establishment of special research centers, where the differing skills of many people can be focused on the basic unknowns of mental retardation, such as the causes of mongolism, the effects of malnutrition on the unborn baby, the best methods of teaching language to those who do not learn to speak at the normal time in the normal way, the ways to modify the inappropriate behavior that stands in the way of a retarded child's progress, and the best way to group children in a residential facility.

Congress addressed itself to these recommendations with zeal in the 1963 legislation. This act authorized Federal aid for construction of (1) community facilities for the retarded, (2) exemplary facilities for the diagnosis, care, treatment, and training of retarded children in conjunction with university programs to train professional personnel, and (3) mental retardation research centers.

For 3 fiscal years—1965 through 1967—the Congress gave full and enthusiastic support to these three complementary programs. After a dozen research centers were funded, the construction authority was allowed to lapse. The university affiliated facility program was renewed in 1967, but has been under funded since then. Budgetary stringencies also forced curtailment of the community facilities program, despite the increasing demand around the country; a demand resulting from a peaceful mobilization of concerned citizens in all 50 States who were and are eager to right the wrongs to a long-neglected segment of our population.

We did, in 1967, belatedly provide a staffing provision to complement these community construction grants. Some 285 applications requesting Federal funds totaling $14.4 million for the first year of operation were received against an $8.3 million appropriation for 1969.

All in all, we have made possible 12 research centers, 19 university training programs—out of some 60 proposed—and approximately 300 community facilities.

To the construction of these community facilities we have obligated only $56 million Federal dollars in 5 years, only a trifle more than the President's Panel recommended we put up for each one of 10 years, and less than one third of the total cost of these facilities.

Clearly this work, well begun, is far from finished. Yet all this significant legislation will expire in less than a year.

Responsible State agencies estimate that projects requiring an estimated additional $100 million in Federal funds nationwide are awaiting development pending the availability of Federal support.

The President's Committee on Mental Retardation, created as an ongoing body in 1966, highlighted the problems of inadequate residential care for the retarded in its report MR 68. At least 50 percent of the country's institutionalized retarded live in functionally inadequate buildings whose average age is 44 years. The staff is overworked, underpaid, and often ineffectively used because of inadequate training. Waiting lists for admission of retarded children and adults are long.

Some helpful impact has been felt as small islands of innovation have been created under the Federal programs called HIP and HIST—hospital improvement program and hospital inservice training. These programs are operated on a project grant basis. For the past 3 years, less than $9 million has been appropriated annually.

As a result, scarcely more than half the public institutions for the retarded in the country are benefiting from each, in this, the sixth year of the program.

The President's Committee recommends that funds be made available to all public institutions on the basis of a State plan for bringing present institutions up to standard and developing new types of localized residential facilities which will not have the dehumanizing characteristics often associated with large, remote hospitals. It is time to move from an underfunded project approach to a realistic formula grant approach which includes a direct attack on the problem of inadequate residential care.

The magnitude of the need was already enormous in 1963. The extent of it was better brought home to State officials and responsible citizens by the comprehensive mental retardation planning effort undertaken in every State during 1965–68, with Federal support and encouragement. Each State now has a clearer view of its problems and a clearer idea of its own priorities, and of the steps it must take to meet them. In many States, new agencies have been created within a State government to spearhead the new efforts, to assume increasing commitments and display more effective and diversified capabilities in directing their own State programs.

At the same time, it is being increasingly recognized that mental retardation is frequently associated with other kinds of developmental disability—such as cerebral palsy, epilepsy, congenital malformation, sensory disorders, and the like—and, further, that even the normally intelligent among children and adults with these disorders often have similar problems of special care, training, treatment and living arrangements. They are part of a continuum of disability. Like the retarded, they frequently have certain urgent needs which are not encompassed in any of the Federal programs of which we boast, because they are too young or too old or too handicapped.

For all of these reasons, the time has come to propose new and more comprehensive approaches to the problems of those afflicted with developmental disabilities. I believe that the Developmental Disabilities Services and Facilities Construction Act of 1969, introduced by Senator Kennedy, and which I cosponsored, deserves the support of all of us. I congratulate Senator Kennedy for his initiative in this area and pledge my full support in behalf of S. 2846, the Developmental Disabilities Services and Facilities Construction Act of 1969.

Senator **Kennedy**. Our first witness today will be a group of three distinguished representatives of the Department of Health, Education, and Welfare, who will testify on the status of current Federal programs for the retarded, and present the administration's recommendations with respect to the pending legislation.

The second witness will be Dr. William Gibson, of Ohio State University, who will testify with special reference to the Federal program for university-affiliated facilities for the retarded.

The third witness will be Mr. Sherwood Messner, of the United Cerebral Palsy Associations, who will be accompanied by Mr. Ernest Weinrich. Mr. Weinrich, who is moderately disabled by cerebral palsy, understands the problems of the severely retarded, and will speak for them at these hearings, since they cannot speak for themselves.

The fourth witness will be the Reverend Damien O'Shea, of Westville Grove, N.J., who will testify with respect to the role of private nonprofit institutions in the Federal program.

The magnitude of the problem of mental retradation and developmental disabilities is enormous. Today, there are 6 million retarded persons in the Nation. More than 125,000 babies are born each year who are, or will become, mentally retarded.

Together with their families, the retarded make up nearly 10 percent of our national population; and the cost of their care is several billions of dollars each year.

The challenge we face is immense, and we must make our resources equal to the task.

Mr. Black, you are the first witness, would you please proceed.

STATEMENT OF CREED C. BLACK, ASSISTANT SECRETARY FOR LEGISLATION, HEW; ACCOMPANIED BY JESSE STEINFELD, DEPUTY ASSISTANT SECRETARY FOR HEALTH AND SCIENTIFIC AFFAIRS, HEW; ROBERT JASLOW, M.D., CHIEF, DIVISION OF MENTAL RETARDATION, REHABILITATION SERVICES ADMINISTRATION, SRS; AND EDWARD NEWMAN, PH. D., COMMISSIONER, REHABILITATION SERVICES ADMINISTRATION, SRS

Mr. Black. Thank you, Mr. Chairman. We appreciate your welcome. In addition to Mr. Newman and Dr. Jaslow, I have with me on my right, Dr. Steinfeld, Deputy Assistant Secretary for Health and Scientific Affairs.

It is a privilege to appear today to testify on the progress that has been made under the Mental Retardation Facilities Construction Act and proposals for its extension and amendment.

This legislation, as you know, was initiated in 1963 with the objectives of stimulating the development of needed manpower, research, and a network of facilities for the delivery of services to the mentally retarded. In the years since 1963, progress toward those goals has been significant.

Under the community mental retardation facilities program (part C), for example, 297 projects have been approved. When completed, they will make available modern and efficient facilities to provide services to 30,000 persons who were not being served at all and improved services to another 45,000 persons.

When the present authorization expires on June 30, 1970, about 67 other facilities will have been funded, which when completed will provide services to 15,000 more persons.

Comparable progress has been recorded under the program of initial staffing grants for community mental retardation facilities, which was added to the act by the Mental Retardation Amendments of 1967. These grants are available to assist in the initial staffing of both new facilities and new services in existing facilities.

To date, 237 projects have been funded, providing support for staff to serve over 60,000 retarded. It is expected that by June, 1970, when the present authorization expires, 468 projects will have been funded, providing staff to serve more than 120,000 retarded in their home communities.

The third major effort financed under this act is the university-affiliated facilities program (part B), which provides grants to assist in the construction of facilities affiliated with universities or colleges which offer interdisciplinary training based on exemplary models of comprehensive services to the mentally retarded.

The university-affiliated centers are a major resource for training professional and technical personnel needed to work with the mentally retarded, such as physicians, social workers, nurses, psychologists, special educators, therapists, and rehabilitation specialists.

Through 1969, 18 project have been approved and funded; six have been completed and eight more should be completed within the next 12 to 18 months.

The facilities are coordinating their activities with other community programs, and with State residential programs for the retarded.

As a broad resource for specialized training, continuing education, and the provision of exemplary service in complex cases, they fill a role in the system of mental retardation services similar to that of the teaching hospitals in the health field or the research and training centers in the field of vocational rehabilitation.

Before turning from this brief summary of results thus far to the question of where we go from here, Mr. Chairman, I think it is important that we put this particular legislation into the broader context of our department's total activities in the mental retardation area.

As the members of this committee are no doubt aware, the Mental Retardation Facilities Construction Act is but one part of a much larger effort which spans the entire Deparment of Health, Education, and Welfare.

The impressive scope of these departmentwide activities was described in a report prepared earlier this year for the House Appropriations Subcommittee by the Secretary's Committee on Mental Retardation.

With your permission, I should like to submit a copy of the complete report for the record of these hearings and summarize it briefly for the purposes of our discussion today.

(The report referred to follows:)

MENTAL RETARDATION ACTIVITIES
OF THE U.S. DEPARTMENT OF HEALTH,
EDUCATION, AND WELFARE

Prepared by Secretary's
Committee on Mental Retardation

Prepared for House
Appropriations Subcommittee

January 10, 1969

SUMMARY OF MENTAL RETARDATION ACTIVITIES

The 1969 Appropriations Act of the Department of Health, Education, and Welfare makes available over $507,963 million for mental retardation program activities in the current fiscal year. Of this amount $198,700 is to be used for income maintenance of persons who are mentally retarded. 1/

The mental retardation activities of the Department have been arranged according to the following categories: preventive services, basic and supportive services, training of personnel, research, construction, and income maintenance.

Preventive Services

Preventive services are defined as those services rendered as a part of programs designed to reduce the incidence of mental retardation. The major programs in this area are administered by the Children's Bureau, Social and Rehabilitation Service. Maternity and Infant Care Projects support programs which provide necessary health care to prospective mothers in high risk populations. By December 1968, fifty-three such projects were in operation. Grants which support screening programs for phenylketonuria (PKU) and other metabolic diseases also are awarded by the Children's Bureau. As of December 1968, forty-three States had enacted laws related to PKU, most of them making screening for this disorder mandatory.

The Public Health Service carries on preventive services in relation to the health services provided beneficiaries of the Service.

Basic and Supportive Services

Basic and supportive services are defined as those services rendered to or for persons who are mentally retarded.

State health departments, crippled children's agencies and State welfare agencies use funds administered by the Children's Bureau for programs designed to: increase the health and welfare services available to the retarded, enlarge existing mental retardation clinics by adding clinic staff, increase the numer of clinics, begin evaluations of children in institutions, extend screening programs, provide treatment services for physically handicapped retarded youngsters, increase inservice training opportunities, and provide homemaker and other care services for the mentally retarded.

The mentally retarded receive a variety of services through the vocational rehabilitation program supported by the Rehabilitation Services Administration: medical diagnosis, physical restoration, counseling and testing during the rehabilitation process, assistance in job placement and follow-up to insure successful rehabilitation. Public Law 90-391, "Vocational Rehabilitation Act amendments of 1968," will assist in the rehabilitation of additional mentally retarded persons to productive life.

The Health Services and Mental Health Administration, in conjunction with the Division of Mental Retardation, Rehabilitation Services Administration, support projects for the retarded which have service components of well integrated

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1/ A Table of Obligations for Fiscal Years 1966-1968 is included on page 65.

comprehensive health programs.

The Division of Mental Retardation through its initial staffing grant program is able to provide part of the initial cost of professional and technical personnel in the operation of new facilities or new services in existing facilities for the retarded. Over $8 million was appropriated in fiscal year 1969 for this program.

In addition, the Division of Mental Retardation also supports two programs directed at improving the quality of State institutional care and treatment for the mentally retarded. These programs are the Hospital Improvement and Hospital Inservice Training Programs.

With the enactment of the Elementary and Secondary Education Act of 1965 (P.L. 89-10) and its subsequent amendments, has come a number of new programs and services for the mentally retarded. The mentally retarded have especially benefitted from the provisions of Title VI of the aforementioned act, which provides opportunities for local school districts to develop new and creative programs for all handicapped children.

Training of Personnel

Training programs form an integral part of most of the mental retardation programs of the Department. These programs include support of professional preparation in the following areas: research training in the basic and clinical biological, medical and behavioral sciences; training of professional personnel for the provision of health, social and rehabilitative services for the mentally retarded; inservice training of workers in institutions for the mentally retarded; teachers and other education personnel related to the education of mentally retarded children; and training of personnel in recreation and physical education activities for the mentally retarded and other handicapped children.

Research

The National Institutes of Health estimates that more than $21,501 million will be devoted in fiscal year 1969 to the support of research related to mental retardation.

The Office of Education administers a program of grants for research and demonstration projects in the field of education of mentally retarded and other handicapped children, and projects related to the application and adaption of communications media to educational problems of the mentally retarded. Title V of Public Law 90-170 provides for grants for research or demonstration projects relating to physical education or recreation for mentally retarded and other handicapped children.

The Social and Rehabilitation Service supports selected demonstration projects that seek to coordinate community resources for the mentally retarded. Particular attention is given to coordination between special education and vocational rehabilitation agencies. Rehabilitation Research and Training Centers for the mentally retarded provide for the diagnosis, evaluation, treatment and training, vocational counseling and placement of the mentally retarded.

Research grants administered by the Children's Bureau support projects directed toward the evaluation of programs and improving the development, management and effectiveness of maternal and child health and crippled children's services.

Construction

The university-affiliated facility and the community facility construction programs are administered by the Rehabilitation Services Administration.

University-affiliated facilities for the mentally retarded provides for training of physicians and other professional personnel vitally needed to work with the mentally retarded. Fourteen applications have been approved and funded under this program.

To date 175 projects for the construction of community facilities for the mentally retarded have been approved. The facilities constructed under this legislation will include a variety of services: diagnosis, treatment, education, training or care of the mentally retarded, including sheltered workshops.

Income Maintenance

The Social and Rehabilitation Service administers the five federally-supported public assistance programs. These programs assist children who are deprived of parental support or care, the needy aged, the medically indigent aged, the needy blind, and the permanently and totally disabled. Mental retardation itself is an eligibility factor only in the category of aid to the permanently and totally disabled.

The social security program, administered by the Social Security Administration, contributes to the maintenance of the mentally retarded through the payment of monthly benefits to eligible recipients.

HEALTH SERVICES AND MENTAL HEALTH ADMINISTRATION

Introduction

The Health Services and Mental Health Administration provides leadership and direction to programs and activities designed to improve physical and mental health services for all the people of the United States and to achieve the development of health care and maintenance systems adequately financed, comprehensive, interrelated and responsive to the needs of individuals and families in all socio-economic and ethnic groups.

More specifically, the Health Services and Mental Health Administration collects, analyzes, and disseminates data on births, deaths, disease incidence, health resources, and the state of the Nation's health. It plans, directs and coordinates a national effort to improve the physical health of all Americans through the development of services to promote and sustain physical health, prevent physical illnesses and provide care and treatment for physically ill persons. And, similarly, it strives to improve mental health by developing knowledge, manpower and services to promote and sustain mental health, prevent mental illness and treat and rehabilitate mentally ill persons.

I. Preventive Services

A. Prevention of Organically-based mental retardation

The prevention of mental retardation caused by organic factors is best accomplished by continuous, comprehensive, and high quality medical care of pregnant women and their offspring throughout the prenatal, perinatal and postnatal periods. The Indian Health Service, through its efforts to provide exemplary medical care to its beneficiaries, is reducing the incidence of organically-based mental retardation as well as the wide variety of other diseases and conditions in mothers and infants which the state of the art in medicine now makes at least partially controllable.

In addition, certain services in prenatal and postnatal care and in family planning are also offered to persons who qualify under community-cooperative programs of the Federal Health Programs Service.

In the 48 Indian Health Service general hospitals which operate obstetrical services, comprehensive prenatal and neonatal care is given specifically to reduce the incidence of mental retardation. Phenylketonuria (PKU) tests are performed on all newborn infants, and infants with a depressed Apgar score or who are prematurely born are evaluated for PKU or other evidence of brain damage.

Both the Indian Health Service and the Federal Health Programs Service provide comprehensive medical care during prenatal, perinatal and postnatal periods. In the Federal Health Programs Service patients of the Federal Health Programs Service who may need specific information on genetic studies or genetic counseling are referred to other agencies for such help; whereas the Indian Health Service attempts to provide genetic counseling when it is indicated.

The Indian Health Service has increased the number and frequency of maternal clinics for Indian mothers during the prenatal period and has also expanded its measles immunization program for Indian and Alaska Native children, to help prevent the measles encephalitis which has a high residual of brain damage of which mental retardation can be one of several adverse consequences.

The Indian Health Service continues to develop its PKU blood screening program concurrently with the development of laboratory facilities by States in which their facilities are located. Individual Indian Health Area Offices cooperate with State and local health departments and regional offices in planning mental retardation programs made possible through grants-in-aid funds from the Children's Bureau. Also, the Indian Health Service is working with the Children's Bureau to determine the best utilization of the professionally trained nurse-midwife in the prevention of mental retardation through improved care of expectant mothers and newborn infants.

Recent studies have indicated the value of child-spacing as a measure to prevent mental retardation. An active family planning program is conducted by the Indian Health Service. Family planning assistance, as one phase of the health and welfare continuum is much broader than birth control and includes infertility services as well as the promotion of responsible parenthood. In this broad concept it is implemented in the Indian Health Service. Since the inception of the family planning program in fiscal year 1965, 21,477 female Indian beneficiaries were provided with birth control services (28.5 percent of female Indian beneficiaries 15-44 years of age). In fiscal year 1968, 11,200 women were rendered birth control services with 23,800 visits to physicians.

The National Communicable Disease Center through its Measles Immunization Program has all but eliminated this once common childhood disease. In fact, by the end of 1968 over 30 million children had been vaccinated against measles. Measles morbidity is now less than one-tenth of that reported only two years ago, and with the current emphasis on improved measles surveillance, the actual decrease may be considerably greater. As a corollary to the near eradication of this disease, the problems of measles-associated encephalitis and mental retardation are also diminishing.

The Immunization Program of the National Communicable Disease Center has provided the leadership of the national measles eradication effort. Working through 72 grant-assisted State and local health department projects which serve over 90 percent of the nation's population, the Immunization Program has collaborated with numerous health agencies in conducting community-wide measles immunization campaigns, and in establishing more effective infant immunization programs. It is conservatively estimated that 25 million cases of measles, 25 thousand cases of measles encephalitis, and over ten thousand cases of mental retardation have already been prevented. Aside from the immeasurable humanitarian benefits accrued from reduced suffering, the economic benefits resulting from reduced health care costs and from savings in educational time and funds lost through school absenteeism, have already far exceeded and more than justified the funds initially appropriated for this effort.

B. Prevention of functionally-based mental retardation

As part of the ongoing comprehensive health program on Indian reservations, mental health projects include prevention, detection, and treatment planning for functional mental retardation. The Indian Health Service is cooperatively working with Head Start Program throughout all of its areas.

II. Basic and Supportive Services

A. Foreign Quarantine Program, National Communicable Disease Center

This program has worked closely with other Federal agencies and voluntary groups to make the best possible arrangements for the reception and treatment of the mentally retarded coming to this country as immigrants.

Mental retardation is one of the conditions specified in the Immigration and Nationality Act causing an alien to be considered ineligible to receive a visa except under waiver. The program is responsible for the review of findings in such cases and the decision on the suitability of proposed care.

For those mentally retarded aliens admitted to the United States, the Service is responsible for complete reports and review of arrangements for treatment in this country. A record is then kept covering the first five years of the individual's treatment in this country, which must be provided in institutions or special facilities approved by the Public Health Service. Semi-annual reports showing kind of treatment and progress made are required and kept on file at the Quarantine Station in New York.

B. Medical and Social Services for American Indians

Medical services and medical social services are provided either directly, under contract, or through State Crippled Children's Services to all Indian beneficiaries discovered to be mentally retarded.

Because of cultural barriers and transportation problems, case-finding continues to be a major problem in this area.

III. Professional Preparation

A. Indian Health Training Programs

The Indian Health Service conducts [illegible]ician residency training programs in pediatrics in its hospitals at Phoenix and Anchorage. This includes clinical training in the prevention, diagnosis, treatment, and rehabilitation of mental retardation.

The Indian Health Service continues to provide both in-service and out-of-service training in maternal and child health nursing to ensure continuity of service from hospital to home and community. An average of 12 nurses are trained each year. The Indian Health Service continues to develop and use coordinated teaching guides for hospital and public health nursing personnel, designed as aids in teaching and good health practices to maternity patients and their families.

B. Education and Training Efforts by the Bureau of Health Services

Coping with mental retardation among its legal beneficiaries is only one of the many health responsibilities for which Bureau of Health Services personnel must be prepared; nevertheless, several aspects of the Bureau's training program are clearly relevant and important to the attack on mental retardation.

Post-graduate training programs in Public Health Service Hospitals include rotating internships, and residencies in internal medicine and obstetrics which involve maternal and pediatric clinical training and the diagnosis and treatment of mental retardation as it arises in the patient population. Research training is conducted in matabolism and endocrinology, disciplines basic to some forms of mental retardation.

C. Training Efforts of the National Institute of Mental Health

The President's Committee on Mental Retardation recommends "greatly expanded" support and increased effort " . . . to attract scientists and professional specialists in education, the medical and behavioral sciences and related fields into research and service . . ." Since the Inservice Training Program in Mental Retardation has been transferred from the Institute, the National Institute of Mental Health supports no training program specifically focused on the field of retardation. A number of programs, however, incorporate some emphasis on the area. Residency training in basic and child psychiatry, for example, includes education in mental retardation as a standard part of the curriculum. Also, training in psychiatric social work and other behavioral science areas includes field or classroom work in mental retardation.

The training programs vary widely in mission and content. Psychiatric residencies include training in intake, diagnostic, and evaluative studies of the retarded, as well as psychotherapeutic work with the emotionally disturbed retarded and their families. Pre- and post-doctoral training in clinical and school psychology includes instruction as well.

It should be noted that the subject of retardation is an element in all undergraduate nursing education and in most of the curricula integrating psychiatric and behavioral science concepts.

In summary, mental retardation is a multifaceted program area which incorporates many of the Institute's focal concerns such as the study and remediation of learning difficulties, cultural deprivation,and the enhancement of optimal development. The breadth and ramifications of mental retardation research makes it critical to the extension of knowledge in the mental health field.

D. Partnership for Health Training Activities

The Partnership for Health Amendments of 1967 (P.L. 90-174) through Section 314(c) authorized project grants for training, studies, and demonstrations in health planning. Public and nonprofit agencies and organizations are eligible to apply for such support. During the fiscal year 1968, $1,410,000 was obligated through the Partnership for Health Program for mental retardation training activities.

IV. Research and Development Activities

A. Research Related to Organically-Based Mental Retardation

A pilot project conducted by the Indian Health Service in cooperation with the Bureau of Indian Affairs utilizes an interdisciplinary approach to identify both organically and functionally retarded children. The medical, psychological and sociological screening of these children provides a diagnostic basis for determination of required medical treatment and specialized curriculum to meet individual learning needs. In fiscal year 1970, this will be expanded and will be involving a number of medical schools located near reservations.

A study recently completed on the White River Reservation showed a correlation between cultural and social problems and incidence of prematurity, which frequently accompanies mental retardation.

A five-year study of American Indian Congenital Malformations, carried out jointly by the Indian Health Service and the Human Genetics Branch of the National Institute of Dental Research, is in its fourth year. When completed, the study will supply data that will help to evaluate congenital defects in relation to total health status of the Indian. It will also help to identify high frequencies of specific defects due to causes which can be remedied, and will make possible racial comparisons of congenital defects which are of basic genetic interest in trying to determine the etiology of these defects.

A long-term study of a group of 643 Alaskan Eskimo children born between 1960 and 1962 is continuing under the joint sponsorship of the Arctic Health Research Laboratory and the Indian Health Service. A recent report on the growth, morbidity and mortality of these children was presented at the American Public Health Association meeting November 13, 1968.

B. Research Concerning Functional Mental Retardation, National Institute of Mental Health

Over the past decades, the National Institute of Mental Health (NIMH) has supported a broad range of research and training projects in the field of mental retardation. In the past several years, new and reorganized agencies within the Department of Health, Education, and Welfare have enlarged their programs in mental retardation, absorbing a variety of NIMH efforts - particularly in the areas of demonstrations, inservice training and basic research in child development. Summarized below are those research and training programs which remain as part of the Institute's overall mental health mission.

In the report MR 68: The Edge of Change, the President's Committee on Mental Retardation recommends ". . . intensification of research in the social and other behavioral sciences . . ." to isolate and define social and cultural factors in mental retardation (p. 25). The current NIMH research effort in retardation is consonant with this recommendation, falling into three categories: (1) studies of learning, with careful attention to the special learning problems of the retarded; (2) analyses of the effects of cultural and social deprivation; and (3) studies of the behavioral and biological aspects of retardation which relate to mental health and illness.

In the area of learning, investigators are conducting a variety of analyses of the learning process as it operates among the mentally retarded, with a view toward identifying those interventions and those techniques which may facilitate the learning process. Such variables as attention span, capacity for retention, distortions of perception and visual discrimination are being scrutinized to increase the retardate's ability to absorb and profit from his experiences, and to facilitate his intellectual and social development. A specific goal of this work is to develop improved teaching methods. For example, automated teaching techniques are being used in several studies, focusing on programmed learning to develop reading and other skills. Although a number of programs involve attempts to help already damaged children, a primary emphasis overall is the prevention of retardation in high risk populations.

In studies of cultural and social deprivation, investigators are defining the role of poverty, inadequate schooling and community disorganization in causing or contributing to various forms of mental retardation. The aim here is to provide new training and educational approaches for culturally handicapped children; to teach improved child-rearing practices to parents in deprived areas; and to modify attitudes of fear and rejection of the mentally retarded among those who are themselves economically and culturally deprived. Approaches range from broad interdisciplinary efforts to establish controlled therapeutic settings, to the development of skills such as operant conditioning among those who attempt to teach the retarded self-sufficiency, self-control, and social adjustment.

In studies of behavioral and biological aspects of retardation, investigators are concerned with developing improved techniques for diagnosing and treating those psychological and physical abnormalities found among the retarded. A major issue here is the degree to which emotional factors contribute to retardation - the role of psychopathology and personality disorganization in the retardate's patterns of functioning. As in the case of such disorders as schizophrenia, the relative contribution of biological, social, and psychological factors remains to be accurately defined.

V. Construction

A. Community Mental Health Centers

Public Law 88-164, passed in 1963, authorized the NIMH to finance up to two-thirds of the cost of construction of new facilities or renovation of existing facilities for a community mental health center. Related legislation passed in 1965 authorized the NIMH to make grants over a 51-month period to community mental health centers to cover part of their cost of professional and technical personnel. To be eligible for either construction or staffing grants an applicant must present a plan for providing a program of at least five essential services of a community mental health center, namely, inpatient, outpatient, partial hospitalization, emergency, and consultation and education. These must be offered in a comprehensive and integrated fashion to the center's community, defined as a catchment area of 75,000 to 200,000 persons. These centers, in which the mentally retarded are eligible to receive treatment and services, serve as the nucleus of the National Mental Health Program. Working in unison with other facets of the national programs in mental retardation and mental health, the NIMH assists States and communities to achieve comprehensive treatment in the community for all who need it. Prevention of mental illness in the community is also one of the major objectives of the centers.

Institute data reveal, for example, that nationally, an estimated four million children under the age of 14 are in need of some kind of psychiatric help because of emotional difficulties. Other estimates are that from 10 to 20 percent of school children show symptoms indicative of pathology which require at least preventive mental health services.

Since the passage of the Community Mental Health Centers Act, the NIMH has supported the development of hundreds of community mental health centers in 49 States, the District of Columbia, and Puerto Rico. The services and programs of many of these centers extend to and include mentally retarded persons. Seventeen percent of the centers funded so far are located in cities of a half-million or more persons; 50 percent are in cities of 25,000 to 500,000, and 33 percent are in cities of 25,000 of less. Centers have been funded that will serve 21 percent of the 500 poorest counties in the United States.

VI. Other Activities

A. Partnership for Health

The Partnership for Health Amendments of 1967 (P.L. 90-174) expanded and extended through fiscal year 1970 the authorizations contained in Sections 314(a), (b),(c),(d), and (e) of the Public Health Service Act, as amended by P.L. 89-749. Grants under Section 314 are administered through the DHEW Regional Offices.

1. Section 314(a) authorized formula grants to States for comprehensive health planning, which would include mental retardation, among other physical, mental, and environmental health concerns.

2. Section 314(b) authorized project grants for areawide comprehensive health planning (including mental retardation). Public and nonprofit private agencies or organizations are eligible to apply for such support.

3. Section 314(c) authorized project grants for training, studies, and demonstrations in health planning. Public and nonprofit private agencies and organizations are eligible to apply for such support.

4. Section 314(d) authorized formula grants to States for public health and mental health services. Mental retardation programs may be supported in accord with a State's plans for health services or mental health services.

5. Section 314(e) authorized project grants for health services development. Public or nonprofit private agencies, institutions or organizations are eligible to apply for such support. Mental retardation projects (including related training) should be for service components of well-integrated comprehensive health services programs. Highest priority will be given to project applications which provide previously unavailable special health services to the mentally retarded or their families as integral parts of programs for model cities, ghettos, neighborhood health centers, family planning, or coordinated health programs.

Since 1964 a mental retardation information activity has been operated as part of the National Clearinghouse for Mental Health Information. Because knowledge about mental retardation comes from many scientific disciplines and professions, this service will improve both research and practice and thus have a decided effect on the prevention and treatment of mental retardation.

To maintain this service, the National Clearinghouse for Mental Health Information has had until September 1968, a contract with the American Association on Mental Deficiency to collect current literature on mental retardation, write informative abstracts, index the literature in depth, compile annotated bibliographies on special topics and prepare critical reviews.

From 1964 to 1967 a total of 12,500 current articles, books and monographs were collected, abstracted and indexed in the Clearinghouse system. To provide a more extensive coverage of information for retrieval purposes, an additional 3,500 indexed abstracts of documents published from 1957 through 1963 were added to this system.

Special annotated bibliographies have been prepared on: (1) Programmed Instruction for the Retarded; (2) Literature for Parents; (3) Application on the Stanford-Binet and Wechsler Intelligence Scales with the Mentally Retarded; (4) Nursing and Mental Retardation; (5) Family Care and Adoption of Retarded Children; (6) Psychotherapy with the Mentally Retarded; (7) Recreation for the Retarded; (8) Counseling Parents of the Mentally Retarded; (9) Sheltered Workshops for the Mentally Retarded; (10) Films on Mental Retardation; (11) Psychopharmacological Therapy with the Mentally Retarded; (12) Electroencephalographic Studies Relating to Mental Retardation; (13) Hydrocephalus; (14) Mental Retardation and Religion.

Review articles and critiques have been prepared on: (1) Mental Retardation; Definition, Classification, and Prevalence; (2) Research on Linquistic Problems of the Mentally Retarded; (3) Attendant Personnel: Their Selection, Training, and Role; (4) Research on Personality Disorders and Characteristics of the Mentally Retarded; (5) Effects of Severely Mentally Retarded Children on Family Relationships; (6) Factor Analysis and Structure of Intellect Applied to Mental Retardation; (7) Counseling Parents of the Mentally Retarded; (8) Genetic Aspects of Mental Retardation; (9) Instrumental Learning in Mental Retardates; (10) Vocational Rehabilitation of the Mentally Retarded: The Sheltered Workshop; (11) Relationships Between Educational Programs for the Mentally Retarded and the Culturally Deprived; (12) A Decade of Research on the Education of the Mentally Retarded.

The abstracts, annotated bibliographies and reviews appear in the quarterly journal, Mental Retardation Abstracts, which is distributed gratis to approximately 7,600 individuals engaged in research and practice in mental retardation and is also for sale by the Superintendent of Documents.

In September 1968 the Division of Mental Retardation, Rehabilitation Services Administration, Social and Rehabilitation Service, assumed responsibility for the contract with the American Association on Mental Deficiency for the collection and abstraction of documents and preparation of Mental Retardation Abstracts, beginning with Volume 6, No. 1, January 1969. The Division is making plans to develop its own data processing and information services program.

In the interim, the Clearinghouse, in order to provide uninterrupted service, continues to answer inquiries in the mental retardation field. Furthermore, the National Clearinghouse for Mental Health Information, in accord with the Institute's current programs in mental retardation will continue to acquire and disseminate information on mental retardation as it relates to: (1) the learning process, learning disorders, and other broad developmental issues with applied applications; (2) emotional and biological conditions as etiology or effect of mental retardation; (3) social and cultural factors as etiology or effects of mental retardation.

B. Institutional and Case Statistics

1. Inpatient facilities: Information is obtained from public inpatient mental retardation facilities, on such patient characteristics as age, sex, medical classification, measured intelligence level for first admissions, and for resident patients.

2. Outpatient Psychiatric Clinics: Information is obtained on the number of terminated patients diagnosed with mental retardation, by age, sex, and degree of deficiency (mild, moderate, severe), whether treated or not treated.

3. Maryland Psychiatric Case Register: Data are routinely collected on demographic patient characteristics, type of service, referral service, and disposition of all patients diagnosed as mentally retarded in all psychiatric clinics and public and private institutions for the mentally retarded.

NATIONAL INSTITUTES OF HEALTH

Introduction

Mental retardation today afflicts the lives of an estimated 6 million persons in the United States. Its impact is directly felt by the some 20 million family members who share the burden and problems of care of the retarded whose inadequate intellectual development impairs their ability to learn and to adapt to the demands of society.

The causes of mental retardation are multiple and involve both physical and environmental factors operating singly or in subtle interactions. Resolution of this complex problem requires the scientific talent from many disciplines--biological, behavioral and social--in a concerted effort involving basic, clinical and applied research over an age span from conception through maturity. The Institute's program of research and research training support represents a major arm of our nation's effort to combat the problem of mental retardation which ranks as a major health, social and economic problem.

In fulfillment of its responsibilities in this area, NIH is supporting a broad attack upon the problems associated with mental retardation. The goals sought are the prevention of mental retardation in the future, the cure of existing mental retardates, or, if this is not possible, the amelioration of their condition and the training and upgrading of such individuals to a point where they can come as close to self-sufficiency as their endowment permits. To these ends the Mental Retardation Program is facilitating research on the diagnosis, prevention, correction and amelioration of mental retardation. Investigations are being supported in basic sciences, both biological and behavioral, as well as clinical disciplines.

I. Training of Personnel

A. National Institute of Child Health and Human Development (NICHD)

The critical need for more research workers from all fields whose primary interests lie in areas related to mental retardation continues. This is evident from the strenuous recruiting efforts which have been observed in the staffing of the Mental Retardation Research Centers, even those whose construction is not yet completed. Fortunately the research training programs have resumed the growth which they were undergoing in fiscal year 1966 and fiscal year 1967. From 13 training grants providing training for 60 trainees in fiscal year 1968, the program has grown to 18 training programs serving 124 trainees. The areas in which training is available under these 18 grants are as follows: behavioral studies - 7; basic biomedical studies - 1; sociology - 1; combined behavioral, clinical and basic biomedical studies - 2; combined clinical and basic biomedical studies - 6; combined clinical and behavioral studies - 1. Of the 124 trainees being served by these programs 76 were predoctoral, 7 received Master of Arts degrees, 25 were in Ph.D. or M.D. programs, 6 received Ph.D. or M.D. degrees, and 10 were postdoctoral trainees. In addition to the trainees who received stipends from these programs several program directors pointed out that a total of 63 other students in a variety of programs benefited from the existence of these NICHD research training programs. These were individuals who participated in the same training courses as those receiving stipends and also worked in research programs alongside those receiving stipends. These additional trainees were supported by other programs, either Federal or local but were able to take advantage of courses and research programs which were instituted under NICHD funded training programs.

In addition to the trainees under these programs the Institute is supporting on an individual basis 9 Fellows and 4 Research Career Development Awardees. In addition to these individuals whose programs are specifically directed towards research in mental retardation the NICHD currently supports fellowships, research career awards, and training grants in areas which are highly relevant to mental retardation but which are funded under other programs. There is a large amount of interaction between the Mental Retardation Program and other Programs in the NICHD such as the Growth and Development Program, the Reproductive Biology Program and the Perinatal and Infant Mortality Program.

B. National Institute of Neurological Diseases and Stroke (NINDS)

While the training program of the National Institute of Neurological Diseases and Stroke is not specifically and exclusively directed towards mental retardation, it is directed toward the development of clinical neurologists and competent research scientists in the fields associated with the diseases of the nervous system. These disciplines provide the basic tools required for any serious attack on the problem of organically-based mental retardation. Particularly important are the Institute programs for the training of pediatric neurologists, who are very often required to make the initial diagnosis of mental retardation. Training programs in speech pathology and audiology are fundamental to therapy in the mentally retarded and receive strong support from the Institute.

II. Research

A. National Institute of Child Health and Human Development (NICHD)

Scientists being supported to work in mental retardation are utilizing a vast array of techniques from the classical observation and descriptive techniques all the way to the most advanced and sophisticated electronic recording and statistical methods. Since for some kinds of work it is neither feasible nor desirable to use human subjects a number of investigators are currently attempting to develop appropriate animal models for research use.

The biological sciences are moving on a broad front from highly advanced biochemical macromolecular investigations through cellular levels to whole organ studies on through research in primates and humans. Clinical specialists are using very delicate and complex diagnostic techniques which could not even have been considered as little as five years ago. In a few fortunate cases, such as some of the diseases from inborn errors of metabolism, therapeusis is also at a level of sophistication which would not have been thought possible only recently. Behavioral scientists, ranging from psychologists through psychiatrists, and sociologists are steadily refining their tools for diagnosis and treatment. This is evidenced by the ever increasing numbers of subentities being identified under the main heading of mental retardation which at one time was an indivisible term. More and more attention is being paid to disorders of communication and perceptual visual problems so that both diagnosis and remedial training moves a little closer to the ideal.

The complexity of mental retardation requires multidisciplinary research approaches and it is encouraging to observe that not only are the obvious combinations such as biochemists working with psychopharmacologists becoming more and more common but less expected combinations such as behavioralists working closely with clinical and basic scientists are beginning to be seen. The Mental Retardation Research Centers which are funded by Congress under specific construction legislation (P.L. 88-164) are serving to facilitate this kind of interdisciplinary effort.

In fiscal year 1969 approximately 270 investigators in 28 specialties or subspecialties are being supported. Some of these specialties are pediatrics, psychology, psychiatry, biochemistry, genetics, education, nutrition, pathology, neurobiology, physiology, anatomy, communications engineering, mathematics, microbiology, obstetrics and gynecology, radiology, social work, sociology, veterinary medicine, and virology. Many of these investigators while working independently are finding it to their mutual advantage to discuss problems with each other and to utilize the insights and techniques of each others' specialties in their own work. The Centers are providing a setting where this is especially easy since in many cases they are, or will be, working in the same physical structures. NICHD staff are encouraging as much as possible interdisciplinary approaches, staff seminars, and other administrative means of obtaining multidisciplinary efforts. It is interesting to note that even in those Centers which have not yet completed their construction that the same kinds of staff interactions are occurring. The required planning is resulting in consultation across disciplinary lines and this consultation is creating contacts among investigators which might not otherwise have occurred. In many cases these contacts are resulting in scientific interactions to the benefit of the program.

One primary thrust of research supported by NICHD continues to be in cytogenetics and the inborn errors of metabolism which result in mental retardation. Both areas are beginning to take advantage of tissue culture techniques which in the latter case provide large amounts of tissue to work with outside the patient himself, yet with material that responds in many ways as the patient does. In the other case large numbers of cells can be studied to observe what is actually happening in the chromosomes. There is also considerable interplay between the cytogenetic and biochemical study of tissue cultured cells addressing the questions of the relationships between chromosomes, enzymes and end results.

Many research projects being funded are at institutions which now have or will have, operating Mental Retardation Research Centers. Congress, in 1963, recognized the limited resources devoted to mental retardation research and requirements for centers of research competence with special capability for meeting the research demands of this multifaceted program. P.L. 88-164 authorized the construction of Mental Retardation Research Centers for the purpose of finding the causes and means for preventing and ameliorating mental retardation. Implementation of this authority was assigned the NICHD in close cooperation with the Division of Research Facilities and Resources/NIH. The NICHD has continuing responsibility for programmatic development of the centers. When operational the centers will provide the major thrust for the Institute's program to combat mental retardation.

The interval between center construction grant awards and completion of construction represents a significant lapse of time. The Institute has acted to reduce the time lag for bringing the centers to fuller operational strength through interim development and strengthening of existing research activities to be included in the centers on completion of construction. These activities are supported by program project research grants awarded the institutions following competitive review for scientific merit by appropriate National Institutes of Health review committee.

Four of the centers were completed and became operational in fiscal year 1968; these were the Children's Hospital Research Foundation, Cincinnati, Ohio; George Peabody College for Teachers, Nashville, Tennessee; the University of Chicago, Chicago, Illinois; and the University of Colorado Medical Center, Denver, Colorado.

Three centers are scheduled for opening in fiscal year 1969; these are: the University of Washington, Seattle, Washington; Albert Einstein College of Medicine, Bronx, New York; and, the University of California at Los Angeles, Los Angeles, California.

Centers at the University of Kansas, Lawrence, Kansas; University of North Carolina, Chapel Hill, North Carolina; Walter E. Fernald State School, Waltham, Massachusetts; and, the Children's Hospital Medical Center, Boston, Massachusetts, are scheduled to begin operations in fiscal year 1970. Plans for the University of Wisconsin Center, Madison, Wisconsin, call for completion of construction in fiscal year 1971.

Existing programs under center aegis at the University of Kansas are making notable progress on poverty-linked retardation with research support from the Institute. Their research demonstrates the crucial role of disadvantaged mothers in facilitating the development of intelligence in their preschool aged children, means for changing the behavior of mothers in parent-child interactions so that their children learn more readily and the importance of community support and involvement in creating constructive research and service programs for the children of poverty.

Methods for constructive intervention to prevent or ameliorate poverty-linked retardation are, or will be studied at the George Peabody, Wisconsin and North Carolina centers. The George Peabody College Center in Nashville, Tennessee, is well established in its research program to study the effects of different methods of educational intervention.

The University of North Carolina Center at Chapel Hill, North Carolina, plans and is piloting studies concerned with preventing retardation among the disadvantaged through a program stressing psycho-social interventions beginning in early infancy and childhood. Closely related to this effort are parallel studies concerned with the control of infectious diseases in children under group day-care. The importance of these efforts and companion efforts elsewhere is stressed by the fact that large numbers of elementary school aged children from disadvantaged homes in the Chapel Hill area have IQ's below 80.

Staff from the University of Wisconsin Center are currently engaged in a major program of research concerned with rehabilitative approaches and methods for use with the disadvantaged. Basic research in learning and human development will expand and complement these applied rehabilitative efforts when construction of the center is completed in fiscal year 1971.

Focal research efforts concerned with poverty-linked retardation are active or planned at other mental retardation research centers. Among these are studies of epidemiology of poverty-linked retardation at the Albert Einstein College of Medicine Center, New York, and at the University of California at Los Angeles, California.

Longitudinal studies of development from the period of pregnancy through the elementary school years are crucial to our full understanding of aberrant and subnormal development. Too frequently the significant events of pregnancy, the neonatal period and early infancy and childhood are lost to investigators concerned with subnormal development and faulty learning as experienced by the school age child because of lack of resources for systematically relating events from early to later age levels. The mental retardation research centers, as never before, offer great opportunities for the conduct of sound, scientific studies of longitudinal development in retarded populations and populations at risk of becoming retarded.

One of the major longitudinal studies attacking these issues is currently under development by researchers in the neurological sciences at the University of Washington Center. These investigators propose studies relating the carefully studied events of pregnancy and the neonatal period to neurological electrophysiological, and neuropathological data obtained during the neonatal period and early infancy. These data will, in turn, be related to patterns of behavior and intellectual functioning during the school years. Careful clinical supervision and recording of life events by the center's excellent and comprehensive resources for diagnostic, treatment and service follow-up will provide a sound base for obtaining the most meaningful results in terms of developmental outcomes.

A major contribution to the epidemiology of mental retardation is expected shortly with the publication of work by Institute supported investigators from the Albert Einstein Center. The study, conducted in Aberdeen, Scotland, utilizes excellent social background, pregnancy, obstetrical and prenatal data from the total population of births in that city collected since 1951. The Aberdeen population is highly stable and excellent cooperation has been obtained from both the health and educational authorities. These conditions have made possible long-term follow-up studies of children deriving from their well studied births. The investigators, therefore, have been able to relate obstetrical and social antecedents characteristic of the birth of the child to his functioning during the school years. Studies of all mentally subnormal children born in birth years 1952 through 1954 and varying in age from 8-11 years at close of follow-up have been readied for report. The first manuscript will treat the interaction of class, central nervous system damage and psychiatric status with mental subnormality.

The Growth and Development Program of NICHD is involved in several activities directly concerned with mental retardation. Presumptive evidence in a variety of animal species, supplemented by scattered tests in humans, indicates that protein-calorie deprivation may have an inhibiting effect on mental and social development. In animal studies, these effects seem to depend upon fairly acute nutritional deprivation of the type only seen in grossly malnourished children. NICHD has therefore organized several studies in South and Central America where protein-calorie malnutrition is endemic, thereby providing a natural test area for the relationships between nutritional deprivation and intellectual and social development.

The largest of these studies is supported by a contract with the Pan American Health Organization for work to be done in the Guatemala highlands by the Institute for Nutrition of Central America and Panama. This study involves matching pairs of rural, isolated villages on a number of factors, and then providing a protein rich food supplement to one village in each pair. The other village will also receive medical care (but no supplement), with provisions to match social inputs that might positively influence intellectual development. Careful study design permits investigation of a variety of factors such as social status, family interrelationships, and parental expectations which influence child development. Now in its fourth year, the study has just entered the definitive stage with initiation of the supplementation program. Continuous data monitoring will measure intellectual development up through age six.

A second study, also under contract, is designed to study the development of pairs of siblings living in urban ghettos in Bogota, Columbia. These pairs of children, all under the age of three years, will include one acutely malnourished and one adequately nourished child, both of whom will be supplemented throughout the study. This design permits control of genetic variables and, to a considerable degree, the social and environmental factors surrounding malnutrition. Many of the tests being used in the Guatemala study will be used in Bogota, plus other measures for delving more deeply into emotional development. This project now entering its second year, is jointly conducted by Harvard University and the National Institute of Nutrition, Bogota.

Recently awarded grants support two other studies in the Western Hemisphere. In Mexico a small, elegantly designed study is focusing on nutrition of the mother and the infant, including controlled studies of breast milk consumption; premature weaning without adequate nourishing food is increasingly recognized as a probable factor in impaired development of the central nervous system and in possible behavior deficits in deprived children. Another project, in Chili, is utilizing children who have been hospitalized with acute malnutrition at a very early age, often as young as 6-8 months. The behavioral patterns of these children following nutritional rehabilitation are being monitored. A very interesting facet of this project is the development of a method of cerebral transillumination which provides clear indications of fluids within the cranial cavity, thereby indicating the relative reduction in brain size as a result of nutritional deprivation.

While these studies do not relate to severe degrees of mental retardation, they will help provide information on the relationship between the malnutrition in half the world's children and their resultant intellectual, social and physical development. An active program is now underway to locate investigators and opportunities to extend these studies into the United States where ghetto populations may experience varying degrees of marginal malnutrition with only occasional gross situations of the type seen overseas. One research grant to study rural southern populations has been approved and is awaiting funding; several others are in various stages of development.

As a further means of assisting the research community NICHD supports scientific conferences when it is apparent that such conferences will be useful and stimulating. A conference was supported on "Social Science and Mental Retardation: Family Components" which was intended to stimulate social science research in parent-child interactions and other family related aspects of intellectual development and behavior of children. The published proceedings of this conference will be available in January, 1969. A conference of specialists was held this year on the Lesch-Nyhan syndrome which is an inheritable disease of metabolism involving a reduced or absent enzyme. This conference was published in the July-August issue of the Federation Proceedings. Another conference was held in which some 15 specialists in cytogenetics participated in the initial planning for a conference on cytogenetics and mental retardation to be held in June, 1970. This will be the first cytogenetics conference to be devoted primarily and entirely to the problem of mental retardation.

Other programs such as Reproductive Biology, and Perinatal and Infant Mortality cooperate with the Mental Retardation Program in support of research of mutual interest.

Intramurally the NICHD continues to provide clinical service and research in mental retardation at the Children's Diagnostic and Study Branch. The staff of this branch is an interdisciplinary group which works together in research and to treat the whole child. It contains clinical specialists as well as psychologists and social workers who combine their efforts in diagnosing and devising treatment plans for children who are referred to them as a result of observed difficulties in adapting to their environment. This group is currently studying a child with congenital anesthesia to pain, temperature and tactile stimuli, but with normal intelligence. Another child being studied is a case with phenotypic mongolism but genotypically normal leukocytes. Both cases raise very interesting theoretical research questions. Other intramural programs also conduct research of significance to mental retardation, directly or indirectly.

B. National Institute of Neurological Diseases and Stroke (NINDS)

The National Institute of Neurological Diseases and Stroke sponsors no research in mental retardation per se but its interest in mental retardation appears when mental retardation arises as a symptom complication or a sequela of some disease of the central nervous system. Consequently a large number of research projects supported by NINDS can be said to be relevant to mental retardation research, although the interest of the scientist may be in the study of some particular phase of disease rather than in mental retardation research directly. The research projects involved cover nearly all of the scientific disciplines to some degree.

One of the Institute's major efforts which has great interest for mental retardation research is a collaborative project with 14 cooperating institutions investigating the prenatal, perinatal and postnatal factors relating to the development of children. The "Collaborative Study in Cerebral Palsy and Other Neurological and Sensory Disorders in Infancy and Childhood" is following the offspring of more than 50,000 mothers from early pregnancy through labor and delivery until the children are at least through the first year of school. The data are in the process of being analyzed and this project should yield a large amount of valuable information related to mental retardation. The Institute is also supporting epidemiological and genetic studies to establish possible patterns of inheritance or other causative factors leading to neurological disease and mental retardation. These include inborn metabolic errors, chromosomal abnormalities and congenital malformations.

Intra-uterine infections occurring in the first trimester of pregnancy are important factors leading to severe destruction of the brain and major mental impairments. The Laboratory of Perinatal Physiology in Puerto Rico is attempting to determine if the monkey can be used as an animal model for German measles infection. If this proves to be the case research into the mechanisms by which German measles affects the central nervous system will be greatly potentiated.

Research into inborn metabolic errors is being supported in order to discover how early these diseases appear and when to begin treatment. There are more than 200 known metabolic abnormalities of which no more than 6 may be amenable to present therapeutic approaches. Continued study is necessary to enlarge these treatment programs. The biochemistry of these diseases and the relationship of the biochemical activities to brain function are being studied. These studies are directly relevant to the development of mental retardation.

Studies are underway to attempt to link the pathological patterns of brain damage to functional development. In this area the Collaborative Study will be valuable in providing both normative data and incidence statistics relative to mental retardation.

The early diagnosis of mental retardation is frequently extremely difficult. The Institute continues to support programs for the refinement of diagnostic techniques. The problem of minimal brain dysfunction is undergoing reevaluation to assess the current status of and to apply advance techniques to this difficult area.

Mental retardation often follows hydrocephalus and brain tumors in childhood. Development of appropriate surgical or pharmacological therapy remains an objective of the Institute. The Institute is also supporting programs which investigate the mechanisms involved in meningitis or meningoencephalopathy to determine proper preventive and therapeutic approaches.

OFFICE OF EDUCATION

Introduction

Programs dealing with handicapped children in the Office of Education have been placed under the administrative direction of the Bureau of Education for the Handicapped. This is consistent with the efforts of the Office of Education to provide maximum educational programming for all children. The Bureau is responsible for supervising and implementing current and new legislative authorities to provide funds for projects and programs relating to the education, training and research of handicapped children and youth. These children include those who are mentally retarded as well as those who are hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, crippled, or other health impaired and require special education.

The Bureau is specifically charged with the task of helping each handicapped child develop to the maximum those skills and talents which will enable him to become independent and self-sufficient as an adult. The Bureau, through its various support mechanisms, directs programs designed to (1) increase the number of qualified professional personnel; (2) improve educational services in local and State programs; (3) stimulate acquisition, evaluation, and utilization of modern educational equipment, media, and teaching materials; and (4) encourage theoretical and applied research, the use of successfully tested research, and advanced educational techniques.

The Bureau of Education for the Handicapped also assumes a major leadership role in the field of special education. To insure effective and capable leadership, the Bureau maintains a constant state of alertness and keeps attuned to new inputs and changes affecting the area of special education. Indicative of its effort to keep in touch with changes occuring in the field, seven special education conferences were held during the first half of 1968. Regionally located, the conferences were attended by approximately 1,000 special educators from all 50 States representing public school programs, institutions for the handicapped, State departments of education, institutions of higher education, and other public and private agencies interested in serving handicapped children.

The seven conferences provided an abundance of information regarding current problems existing in the field of special education as well as projecting possible avenues for their solution. This information is being analyzed and follow-up conferences will be held to study further the efficacy of the proposed solutions. The follow-up conferences, like the above conferences, will be working conferences with an emphasis on two-way communication between educators in the Federal government and those in the field.

The impetus for change and its challenge is part of the climate of the Bureau. It is reflected in the mood and feeling of its professional staff in their drive for commitment and awareness to innovate, to initiate, to lead, to evaluate, and "to be first" to enter new areas to benefit the handicapped. The Bureau provides leadership at every level to provide resources, knowledge, and awareness not limited by lack of preception, or vision, or by lack of dedication to the handicapped by those responsible for effecting policy.

In order to efficiently implement its assigned responsibilities the Bureau is administratively organized into three major divisions and an Office of the Associate Commissioner which includes a Program Planning and Evaluation Office; an Information and Reports Office; an Executive Office; and an Office for the Development of New Programs. This latter office is responsible for developing guidelines to effectively implement new legislation which expands and creates educational opportunities for handicapped children.

Each of the three divisions provide an important element in the functions rendered by the Bureau in making up a total program of service, training, and research for the mentally retarded as well as other handicaps of children. The following pages describe these services for mentally retarded children on a divisional basis.

I. Division of Research

A. Purpose

The Division of Research promotes and supports research and related activities which show promise of leading to improvement in educational programs for handicapped children. Support is available for research, dissemination, demonstration, curriculum, and media activities.

B. History

The program now-administered by the Division of Research was initiated during fiscal year 1964 with an appropriation of $1 million authorized under Title III, Section 302 of Public Law 88-164. The scope and flexibility of the program has been extended through amendments to this basic authorizing legislation in P.L. 89-105, P.L. 90-170, and P.L. 90-247. Table 1 provides data on the authorizations, appropriations, obligations, and number of projects supported under this program.

C. Impact on the Problem of Mental Retardation

It is difficult to assess the direct impact of research activities since the lag between the discovery of new knowledge and consequent changes in educational practice obsures the picture. However, some information on the impact of the program is available. As of the end of fiscal year 1968 approximately sixty final reports of research monitored by the Division of Research were made available to practitioners in the field. Many of these research projects have also resulted in other publications in the professional literature. Although the systematic collection of data on the actual implementation of research findings from these projects is just beginning, there are many instances in which these findings have had a direct impact on programs for the mentally retarded.

D. Future Goals

The history of research on handicapped children suggests that minimal gains are obtained by spreading research monies too thinly. Many of the most important problems in education require a massive effort if solutions are to be found in time to help today's children. The Division of Research proposes to support the establishment of Research and Dvelopment Centers to focus on the more difficult problems of evaluation, communication, instructional procedures, etc. Through the combined efforts of Research and Development Centers and programmatic research on specific major educational problems it can be expected that new models of instruction will be available within a few years.

At the same time, systems of dissemination will be evolved which will facilitate the acceptance of these new models by local school administrators. The new systems of dissemination will be built upon the foundation of Instructional Materials Centers already developed and a system of regional resource centers currently being developed.

As more funds for research become available, engineering technology will more and more become a part of research supported by this Division. This development has been made possible by the amendment permitting the use of contracts as well as grants for research and development activities. Engineering technology, programmed instruction, and the "systems approach" to education will occupy a major place in the Division's activities in the years to come.

E. Current Activities

The Division currently supports a wide range of activities relating to the education of mentally retarded children. One of the most visible of these is the network of instructional materials centers for handicapped children. Although serving teachers of all the handicapped, these centers have a major commitment to mental retardation. The Instructional Materials Centers, 14 in all, are scattered across the country to serve specified regions. The primary objective of each center is to keep teachers of handicapped children aware of new developments in educational materials. The centers are evaluating existing materials as to their relevance to the handicapped and assisting in the development of new materials. Since the 14 centers are connected as a network, any information located at any center is immediately relayed to all other centers.

The Comprehensive Research and Demonstration Center for Handicapped Children, now under construction at Teachers College, Columbia University, similarly has a major emphasis on the problems of the retarded, although at the same time relating to the educational problems of many categories of handicapped children. This center represents a major investment of research funds, both for construction and operation, in an attempt to develop an intense effort in this area of education.

Other research activities now under way are attacking the problems of teaching and learning with the mentally retarded. One such project has suggested that time spent in learning to learn can make a significant difference in the learning performance of retarded children. Other projects are developing and testing new curricula for the retarded.

Table 1

Division of Research - - - Historical Data

Year	Authorization	Appropriation	Obligations	#Projects
1964	2,000,000	1,000,000	999,739	34
1965	2,000,000	2,000,000	2,000,000	53
1966	6,000,000	6,000,000	5,994,231	133
1967	9,000,000	8,100,000	8,049,041	127
1968	19,500,000	11,100,000	10,794,113	135
1969	21,750,000	13,600,000	---	---
1970	28,000,000	---	---	---

II. Division of Educational Services

A. Purpose

The Division of Educational Services provides direct support to handicapped children through services at the classroom and intermediate levels. The Division offers support to State, regional, and local programs to assist in developing and maintaining leadership in the education of handicapped children.

B. Historical Development

Public Law 85-905, the Captioned Films for the Deaf Law, was passed by Congress in 1958 to provide entertainment films for the deaf. This law has subsequently been amended by P.L. 87-715 in 1962 and P.L. 89-258 in 1965 to allow for training, research, production and distribution of educational material for use by deaf children. In December 1967, this authority was again expanded to include educational services to all categories of handicapped children through the 1967 amendments to the Elementary and Secondary Education Act.

Public Law 89-313 was passed by Congress in November 1965, which extended the benefits of Title I of the Elementary and Secondary Education Act to handicapped children in State-supported programs.

During recent years, as local facilities for the handicapped have increased, State schools have found the composition of their resident populations changing from the mildly handicapped to large percentages of children who are severely mentally retarded, and those who have serious handicaps in addition to mental retardation. Model and pilot programs for these types of children have been conducted under P.L. 89-313 in many States.

These funds have enabled institutions and agencies to develop programs for children who have not previously been considered capable of responding to educational or rehabilitative services. The results in many instances have been encouraging and special educators and staff in residential institutions have raised their levels of expectations for such children. While this program has had a relatively limited funding based upon its authorization, significant results have been realized especially in terms of planning for comprehensive services. Monies allotted under P.L. 89-313 for handicapped children were $15.917 million for fiscal year 1966, $15.065 million for fiscal year 1967, and $24,747 million for fiscal year 1968, and $29.7 million for fiscal year 1969. In fiscal year 1967, 46,645 mentally retarded youngsters were assisted under this program at an expenditure of $8,473,118.

The 1966 amendments to the Elementary and Secondary Education Act provided under Title VI-A, a program of support to local education agencies through a State plan program. While this law authorized $150.0 million for fiscal year 1968, the appropriations were only $14.25 million. For fiscal year 1969, $162.5 million was authorized and $29.25 million was appropriated.

The 1958 amendments to Title III of the Elementary and Secondary Education Act, provide that 15% of the funds for fiscal year 1969 be spent for innovative and exemplary projects for handicapped children. It is estimated that $3 million of the funds for the handicapped under this Title will be expended for services to retarded youngsters during fiscal year 1969.

P.L. 90-247 provides for the development of regional centers for deaf-blind children under Title VI-C. The appropriation for 1969 is $1 million which will be used for both development of programs and for direct services to deaf-blind children and their parents. The law permits use of these funds for deaf-blind children with additional handicaps, including those who are mentally retarded.

The Handicapped Children's Early Education Assistance Act, embodied in P.L. 90-538, provides for establishment of a number of model programs for serving very young children with various handicaps. These programs will be distributed strategically throughout the country to serve as models for the development of future preschool and early childhood programs. The 1969 appropriation is $1 million, which will serve as planning and development funds during the first year of the program.

C. Impact on Mental Retardation

Programs will have a significant and far-reaching impact upon education and rehabilitation of mentally retarded individuals. Through such direct support programs Title VI (aid to local programs) P.L. 89-313 (aid to State programs), more extensive and comprehensive programs will develop which will include the utilization of the latest teaching techniques and educational technology. Media Services and Captioned Films for the Deaf with expanded responsibility should provide for an opportunity for State and local programs to take advantage of educational materials, media, and equipment especially designed to meet the needs of the handicapped.

D. Future Goals

The goals of the Division of Educational Services are to:

1. Provide significant support monies to both State-supported and local educational programs to assure quality education for all handicapped children.

2. Provide intermediate services such as comprehensive educational diagnostic resource centers on a regional base to provide services for handicapped children and their families. In addition to direct services to children, these centers will provide consultative services to State and local educational agencies to assure the latest available information from research with respect to the learning process.

3. Provide wherever needed comprehensive regional programs for severely multiply handicapped children such as deaf-blind children.

4. Provide through media services the research, production, and distribution of specially designed materials and programs for educational technology for handicapped children. To provide training in the use of media for teachers of the handicapped.

5. Provide through Instructional Material Centers educational management and information systems.

E. Current Activities

During 1968, the Division of Educational Services held five Regional Conferences to acquaint Title I (89-313) Title VI-A and Title III Coordinators with exemplary projects for the handicapped. The Division staff met with over 600 professional and interested parties to discuss the overall service program of the Bureau at these conferences.

During fiscal year 1969, the total funds available for services to handicapped children from this Division will exceed $88 million. Most of this money will be made available through State Plan programs. Under the State Plan programs, it is estimated that 25 to 30 percent of the funds will be expended for retarded children.

These programs have led to an interest in comprehensive planning. The Division plans to work with State and project personnel to develop long-range plans and evaluation procedures during 1969. These activities are serving the special educational and related needs of retarded children through such programs as preschool, elementary, and secondary education projects which may include: curriculum enrichment, expansion, and improvement; summer school programs; preschool and school readiness programs; physical education and recreation; prevocational and vocational training; inservice training of teachers; and improved diagnostic services.

III. Division of Training

A. Purpose

The Division of Training Programs initiates, maintains, and improves programs for the preparation of professional leadership and teaching personnel to educate handicapped children. Divisional programs which are designed to implement this purpose are two-fold in their attack, in that they must provide: (1) classroom and administrative personnel for State and local special education programs; and (2) personnel for higher education institutions responsible for preparing administrative and classroom personnel. The Division of Training Programs in an effort to effectively implement training programs for the mentally retarded has organized a Mental Retardation Branch. This Branch, one of three in the Division, is responsible for the coordination and administration of all programs in the area of mental retardation.

B. Need

As more States legislate mandatory education for handicapped children the major problem faced in implementing such legislation is an acute shortage of qualified personnel. Current estimates indicate a need for approximately 300,000 teachers to meet the educational needs of all categories of handicapped children. However, only 70,000 teachers are now available, with the prospect of an additional 21,000 to be trained by 1969. Of the 70,000 teachers available now, approximately one-fourth are not fully qualified. If general turnover rates applicable to the profession are applied, approximately 10% of the special education teachers will leave the field each year. At current rates of preparing professional personnel, sixteen years would be needed to close the gap between supply and demand.

As a result of the teacher shortage, approximately two-thirds of the more than five million handicapped children of school age are not receiving special educational services they require. Many of the established programs are actually of minimal quality, because they have been started with less than fully qualified personnel. This current deficit, as in the past, not only retards the systematic growth of special education, but simultaneously requires the majority of our nation's handicapped children to accept an educational program inappropriate to their needs.

C. History

In 1958, Public Law 85-926 was passed by Congress authorizing an appropriation of $1 million per year for the preparation of professional personnel in the education of the mentally retarded. This initial piece of legislation was directed at preparing college and university personnel to staff the then existing programs, and much needed new programs for preparing personnel to work with the handicapped in State and local school systems. Between academic years 1959-60 and 1963-64, 692 graduate fellowships were granted to 484 individuals. The majority of these individuals became college and university professors while others became State and local special education leadership personnel. In fact, a recent survey made of the above fellowship recipients indicated that approximately 75% of all programs in mental retardation at colleges and universities are directed or coordinated by these individuals.

On October 31, 1963, P.L. 88-164 was signed into law. Section 301 of this act amended P.L. 85-926 to: (1) expand the program to include not just the area of mental retardation, but also the areas of the visually handicapped, deaf, crippled and other health impaired, speech and hearing impaired, and the emotionally disturbed; (2) allow for the preparation of teachers and other specialists in addition to leadership personnel at the graduate level; (3) extension downward into the senior year undergraduate levels; and (4) increase the monies authorized for these purposes. Since P.L. 85-926 was passed in 1958, approximately 17,000 fellowships and traineeships have been awarded to individuals preparing to work with mentally handicapped children. This includes both short term and full academic year awards.

A study conducted in February of 1964, of 245 former P.L. 85-926 fellowship recipients revealed that over 90 percent of them were engaged in the field of special education, including the mentally retarded, and about 70 percent were engaged primarily in the field of mental retardation. Sixty-eight of the 245 former fellows indicated that they were currently employed by a college or university, 80 were employed in an administrative or supervisory capacity (19 of these were employed by State educational agencies), and 54 returned to the classroom as teachers of the mentally retarded.

Public Law 85-926 was further amended with the passage of Public Law 89-105 and 90-170. These amendments expanded and extended the program through fiscal year 1970, authorizing appropriations of $29.5 million for fiscal year 1967; $34 million for fiscal year 1968; $37.5 million for fiscal year 1969; and $55 million for fiscal year 1970. These funds have been, and will be, used as stipends for students as well as to support colleges, universities, and State education agencies with the cost of instruction.

Table I - Awards made in the area of mental retardation since the passage of P.L. 85-926 (Fiscal Years 1960 through 1967)

Fiscal Year	Number of Traineeships & Fellowships	Number of Higher Education Institutions Participating	Number of State Education Agencies Participating	Total Amount Obligated
1960	177	16	23	$ 985,222
1961	164	18	41	993,433
1962	160	20	46	997,000
1963	163	19	48	996,433
1964	2,357	108	50	6,419,332
1965	2,506	153	50	6,569,815
1966	3,110	162	52	7,658,002
1967	3,816	177	53	8,891,072
1968	4,521	177	53	8,493,668
1969**				

**Appropriations will be approximately equivalent to fiscal year 1968 (awards not available at time of this report)

The number of individuals being trained in mental retardation under this grant program is significant. The improvement and expansion of the many teacher-training programs in mental retardation throughout the Nation -- resulting directly and indirectly from the grant program -- will, in the long-run, be of even greater significance. Evidence suggests that the support grants which accompany traineeships and fellowships have enabled a great many of the currently participating colleges and universities to add staff, expand the course offerings, and better supervise the observation and student teaching experiences of the students. The total number of students benefiting from these program improvements at the various colleges and universities will, in most instances, far exceed the number of students who are on a fellowship or traineeship.

It is readily apparent that the "old" P.L. 85-296 program, and its major amendment, P.L. 88-164, has enabled a great number of colleges and universities to develop and/or expand their teacher-training programs in mental retardation. A current analysis of the more than 220 institutions requesting funds in the area of mental retardation indicates that more than 150 of them have on their faculties former fellows who review training under Public Law 85-926.

It will be a number of years before there will be a great reduction in the gap between the number of trained teachers and "leadership personnel" in the area of mental retardation who are needed and the number who are available. However, Public Law 85-926 -- prior to and since the amendments by Section 301 of Public Law 88-164 -- has provided the necessary beginning in the effort to close this gap.

1. Program Development Conference

A two day conference was sponsored during the month of May by the Division of Training Programs for special educators from institutions of higher education which had been awarded new program development grants for fiscal year 1968 (academic year 1968-69). Five new institutions with programs in the area of mental retardation participated, in addition to seven institutions which had received program development grants in the area in fiscal year 1967. During the conference, directors of programs in higher education institutions which had already completed one year on a program development grant communicated their experiences to those just entering their first year. The sharing of ideas by "new" and "old" directors of program development grants was found to be most stimulating and beneficial to all in attendance.

A similar conference is planned for the spring of 1969, for recipients of program development grants for fiscal year 1969.

2. University Affiliated Facilities Conference

A two day conference was held in July to more clearly delineate the role of special education training components in university affiliated facilities for the mentally retarded. Participants included personnel from the Bureau of Education for the Handicapped; Social and Rehabilitation Service; the President's Committee on Mental Retardation; the Secretary's Committee on Mental Retardation; directors of university affiliated facilities; and, Office of Education consultants in the area of mental retardation.

The types of models for interdisciplinary training of personnel to be developed in university affiliated programs; criteria for evaluating such programs; and, projected patterns of funding were discussed. Future conferences of this nature were recommended and are being contemplated for the coming year.

D. Current Activities

The Division of Training Programs in an effort to utilize all resources in the provision of quality educational programs for all retarded children has entered into cooperative funding or working arrangements with other personnel training programs in the Office of Education and the Social and Rehabilitation Service. The following are three examples of the Division's cooperative efforts:

1. Teacher Corps

The Teacher Corps and the Division of Training Programs are jointly supporting a teacher corps program at the State College of Arkansas in Conway, Arkansas. Specifically, the Division provided funds for the support of one teacher corps team (six master's level teachers) who will be instructed in special education of the mentally retarded. Concurrent with their instruction, the teacher corps team members will be working in public school systems with rural disadvantaged children throughout the State of Arkansas.

2. University Affiliated Facility Program

The Division of Training Programs in cooperation with the Division of Mental Retardation within the Social and Rehabilitation Service provided monies to support special education components in six university affiliated facility programs for fiscal year 1968. The extent of the Division's support ranges from approximately $11,500 to $30,000 with a total expenditure of $150,000 for the six supported facilities.

The Division will support a special educator on the university affiliated facility core faculty. The special educator will be responsible for instructing medical students, psychologists, social workers, and other related medical personnel as well as students majoring in special education. He will serve to effectively integrate special education concepts into the over-all interdisciplinary training program of the university affiliated facility.

The six programs funded were: John Hopkins University, Baltimore; University of Georgia; University of Miami, Miami; University of California at Los Angeles; Georgetown University, Washington, D.C.; and the University of Alabama, Birmingham.

3. Education Professions Development Act - P.L. 90-35

The Bureau of Educational Personnel Development and the Bureau of Education for the Handicapped have agreed to cooperate in the funding or programs which provide special education training to regular educational personnel who are working with handicapped children. Approximately 15 percent of the funds available under Parts C and D of the above Act will be used in programs to train regular educational personnel such as counselors, educational technology specialists, teachers, and administrators who have an interest or need to become more knowledgeable regarding the problems of the handicapped.

This cooperative program is being coordinated through the Division of Training Programs. The Division director works very closely with personnel within the Bureau of Educational Personnel Development in arriving at funding decisions for projects that involve training in the area of the handicapped. All proposals for example, having a handicapped component or orientation are screened initially by the staff of the Division of Training Programs.

When one considers an earlier statement made in this publication to the effect that approximately two thirds of all handicapped children are not receiving specialized educational intervention, it becomes quite obvious that this cooperative agreement will have great impact on improving services for the handicapped. The program, when fully implemented will facilitate greater cooperative interactions between regular and special educators. This will ultimately lead the way to maximum educational programs for all handicapped children.

E. New Programs

1. Special Projects

Training programs to be truly effective must reflect the growth and evolution of special education programs brought about through expansion of research and service activities. As a result training programs must be flexible and enable a continual, but systematic modification of their approaches. Proven traditional approaches to training should be retained, but every opportunity to blend the old approaches with new directions as increased knowledge and experience becomes available, should be encouraged.

To provide means for developing new models in the closing months of fiscal year 1968, the Division of Training Programs implemented a new Special Projects Program Development Grant Award Program. The purpose of the program is to plan; to try new models of training; and to evaluate the effectiveness and efficiency of these new models in preparing personnel to work with handicapped children. These grants are designed to provide the wherewithal for the field of special education to develop, implement, and test new approaches for the preparation of personnel to meet current and projected needs in the education of handicapped children.

There are two types of grants within the special projects award program: planning and prototype (including evaluation). Planning grants will be utilized to provide funds for the support of personnel, travel, and other costs necessary for developing a detailed plan for implementation of a prototype.

Prototype grants will be utilized to implement and test new training approaches. Successfully implemented prototype grants which provide viable approaches to training will be placed into the regular award program for future funding to other training agencies in the United States.

Six planning grants were awarded for fiscal year 1968, in amounts ranging from $12,900 to $28,998. The universities receiving the initial awards were: American University; University of Minnesota; George Peabody College; Southern Connecticut State College; University of Illinois; and the University of Iowa.

2. Training of Physical Educators and Recreation Personnel

In addition to the amendments of 85-926 cited earlier, P.L. 90-170, Title V established a program entitled "Training of Physical Educators and Recreation Personnel for Mentally Retarded and Other Handicapped Children." Section 501 of this bill authorized appropriations of $1 million for fiscal year 1968, $2 million for fiscal year 1969 and $3 million for fiscal year 1970.

The Bureau of Education for the Handicapped through the Division of Training Programs will assist universities and colleges in providing advanced professional training to physical educators and recreation personnel working with handicapped children. It is anticipated that planning and program development grants will be awarded to approximately ten to fifteen schools of physical education or recreation to establish graduate level curriculum related to the preparation of college instructors, to some short term training courses designed to stimulate better programming for the handicapped child.

An appropriation of $300,000 was made for the implementation of this program in fiscal year 1969.

F. Future Goals

The goals of the Division of Training Services are to:

1. Develop "quality" personnel preparation programs at all levels -- undergraduate through graduate.

2. Provide greater opportunities for the interaction of Division staff with university personnel regarding issues in the training of professional personnel.

3. Establish a clear and well defined "State of the Art."

4. Continue cooperating with State departments of education to effect comprehensive planning for the training of personnel in special education.

5. Provide continued leadership to the developing university affiliated programs to insure the incorporation of strong special education components into each program.

6. Produce informative materials concerning the education of mentally retarded children and the training of professional personnel to work with them in educational and related placements.

7. Develop realistic new training programs for personnel at pre-school and work-study levels.

8. Effectuate qualitative evaluation of all current programs preparing personnel in mental retardation.

IV. Other Office of Education Programs for the Mentally Retarded

The Cooperative Research Act (P.L. 89-10, Title IV) is supporting several projects concerned with mental retardation. Some of the activities funded under this program touched upon the development of a project for educable mentally retarded children to receive vocational training in food service; the relationship between the training experience and certain personality characteristics of teachers and the progress their trainable mentally retarded students made; and a comparison of two learning and retention techniques with mentally retarded children.

The Vocational Education Amendments of 1968 provide that at least 10 percent of each State's allotment for basic grants must be used for programs for persons who are handicapped, including persons who are mentally retarded or seriously emotionally disturbed. This provision of the Act becomes effective in fiscal year 1970. It is anticipated that about 50,000 mentally retarded persons will be served with about $11,500,000.

SOCIAL AND REHABILITATION SERVICE

Introduction

The Social and Rehabilitation Service (SRS) was established August 15, 1967, by the Secretary of Health, Education, and Welfare to join under a single leadership the Department's income support programs for needy Americans and the social and rehabilitation programs that many families and individuals need.

The organization is designed to provide a stronger emphasis on rehabilitation in social and welfare programs.

Key features of the organization are:

--The uniting in a single agency of the various HEW services that deal with special groups -- the aged, the handicapped, and families, especially children.

--The separation of the administration of income-maintenance programs for needy persons from rehabilitation and social service programs.

--Decentralization of certain authority to the Department's nine Regional Offices and the appointment of a single Social and Rehabilitation Service Regional Commissioner in each region to make it easier for States and communities to do business with the Federal Government.

The five major components of the agency are: the Administration on Aging; Assistance Payments Administration; Children's Bureau; Medical Services Administration; and the Rehabilitation Services Administration.

All of these component agencies have major responsibilities in the area of mental retardation except for the Assistance Payments Administration. The reorganization has placed new responsibilities for the mentally retarded on the Administration on Aging, the Children's Bureau, and the Rehabilitation Services Administration, which are now concerned with the provision of social and rehabilitative services to various categories of public assistance recipients. The Rehabilitation Services Administration also includes the Division of Mental Retardation.

Also located in SRS is the Office of Research, Demonstrations and Training. This office administers a program of grants to States and to public and private, nonprofit agencies to pay part of the cost for research, demonstrations, and the establishment of special facilities and services contributing to the field of rehabilitation.

New legislation has reaffirmed and expanded the Nation's commitment to programs on behalf of the mentally retarded. This includes the Mental Retardation Amendments of 1967, the Vocational Rehabilitation Amendments of 1965, 1967 and 1968, and various aspects of the Social Security Amendments of 1967.

The responsibilities and activities of the component agencies of the Social and Rehabilitation Service and the provisions of the new legislation with respect to programs for the mentally retarded are described on pages 27 to 61.

Office of Research, Demonstration and Training

1. Rehabilitation Research Branch Program of the Research and Demonstration Grants Division

This Branch carries on a substantial program of research on problems of rehabilitation of retardates. Areas covered include evaluation of aptitudes and abilities, analysis of jobs which the retarded can perform, opening of new occupational areas for the retarded, improvement of counseling techniques, development of new methods of training and job adjustment and evaluation of facilities and programs to assist the transition of the retardate from the institution or other sheltered environment to community participation. The 1965 Amendments to the Vocational Rehabilitation Act recognized in particular the needs of retardates by providing up to eighteen months of services during which the individual is evaluated for employment potential. These amendments also recognized the need for continuing care and study in the form of provision for improved workshops for retardates and other handicapped persons.

The Amendments of 1968 have focused attention on the necessity for research on retardation as a function of cultural deprivation. Current programs of research and demonstration are, therefore, increasingly concerned with new approaches to retardation in ghetto areas, and especially model city neighborhoods. Rehabilitation techniques already developed through research are being extended to problems of the hard core welfare client.

Emphasis is placed on the coordination and focusing of all relevant community agencies on the problems of the retarded. Projects in five different cities have demonstrated ways of most fruitfully bringing together the services of agencies involved in programs for the retarded. An additional study evaluated the efforts of one of these coordinated services programs.

Culture-fair assessment of rehabilitation clients has become of increasing importance as selection for jobs has extended to cultural handicaps. A simple pictorial inventory which will assist in solving this problem for retardates is the recently completed Vocational Interest and Sophistication Assessment Test standardized on 3,000 retarded persons and predicting what job an individual will find most satisfying to him in terms of his interests.

A variety of community based projects demonstrating involvement of community resources for training of retarded and for their transition to the wider community are the results of recent research efforts. For example, the San Francisco Aid for Retarded Children, Inc., worked with several retarded adults who had little or no employment background. It was found that 50 percent of the experimental sample could be trained and placed in outside employment. Last year witnessed the completion of a substantial number of work study programs for retarded adolescents. These have been sponsored by State Divisions of Vocational Rehabilitation jointly with local school boards, parent organizations, private schools, and State departments of education. In these projects of even severely retarded adolescents, 40 percent have been placed in outside jobs. All projects were taken over by the community at completion.

The Bourbon County Schools work-study project, one of several in Appalachia, was established in Kentucky, a State with one of the highest dropout rates in the nation. The retarded subjects were children of impoverished parents; the majority were from homes of tenant or farm laborers with earnings well below poverty level. Despite the massive handicaps of cultural deprivation and mental retardation among the youngsters studied, this project, over its three-year term, reported a dropout rate of only 5 percent. Moreover, 88 percent of the sample of youngsters served have been trained and placed in jobs thus contributing not only to their own independence, but also to the economic welfare of their parents and the community at large.

During the past two years the State Divisions of Vocational Rehabilitation have conducted energetic programs to place the retarded in a wide variety of civil service jobs. The District of Columbia, DVR and George Washington University are now engaged in a follow-up study of the first 2,000 mentally retarded workers placed with the Federal government throughout the country to determine how effective the program has been and how to improve and expand it to State governments as well.

In order to accelerate training and make it more widely available, the research program has supported a number of projects demonstrating automated teaching techniques for the retarded. One of these, a research demonstration completed last year by the Devereux Foundation, Devon, Pennsylvania, found that automated teaching methods combined with regular classroom work proved more effective than machine methods alone or classroom instruction alone in enabling retarded students to utilize learned material in a practical work situation. To increase manpower for assisting the retarded, the research program extended support to research demonstrating techniques for training volunteers to work with retardates. The MacDonald Training Center Foundation, Tampa, Florida, last year completed a project that developed effective methods of selecting, orienting, and training volunteers whose activities will supplement services of professionals to mentally retarded persons.

2. Rehabilitation Research and Training Centers Program

The Research and Training Centers Division of the Office of Research, Demonstrations, and Training has responsibility for administering three Rehabilitation Research and Training Centers in Mental Retardation. These centers are distinct organizational and physical entities providing a continuing framework for psychological, social, vocational and rehabilitation research and training, and at least on a demonstration basis, a comprehensive program of evaluation, training, counseling and placement of the mentally retarded individual. The three Mental Retardation Research and Training Centers currently sponsored by the Social and Rehabilitation Service of the Department of Health, Education, and Welfare, are the University of Wisconsin, the University of Texas, and the University of Oregon.

The research conducted by these centers encompasses many aspects of the rehabilitation process, from onset to training and placement of the retarded individual. It is broadly directed to a wide range of psychosocial, vocational, or other fields of rehabilitation, and also to specific problems in the many aspects of rehabilitation of the retarded.

The training program of these centers provide training of all types, long-term as well as short-term, professional, technical, and for all categories of students, graduate or undergraduate, working in the medical, health-related or other professions engaged in rehabilitation. The program provides training in such areas as the principles of rehabilitation of the retarded and the special problems related to individual or groups of educational, psychosocial, vocational, and medical and other disciplines in the practice of rehabilitation. In all instances, training has been based upon a defined, organized program of instruction designed for undergraduate and graduate students, interns, and professional workers in the field of rehabilitation. Selected sub-professional workers have also been trained.

In 1968, the three Mental Retardation Centers conducted 51 research projects. Of this number, eighteen are continuing to seek out the cause of retardation, to assess the potential for education and rehabilitation, to develop training and remedial programs suited to the needs of the retarded, and to ascertain the actual learning and socialization difficulties encountered by the retarded. Also being emphasized is the development of adequate motivation for work in the retarded through family, school, and community resources.

The Mental Retardation Research and Training Centers have proposed more than thirty continuing projects directed to the analysis of behavior of the retarded in a variety of settings, the socialization processes, and the mechanisms of acquiring adaptive behavior. Such studies will enable new conceptualizations, not previously available, to be utilized in preparing the retarded for productive, independent living. This research knowledge will also be helpful in planning and developing remedial and rehabilitation programs for the disadvantaged and culturally deprived in becoming more self-sufficient.

As an example, a "high-risk" population laboratory has been established by the University of Wisconsin Research and Training Center in the Milwaukee innercity area of economic and cultural deprivation, which is characterized by an extremely high incidence of mental retardation. Studies revealed that although the area comprises only 2½ percent of the city's population, it yields 33-1/3 percent of the total number of children identified as educable mentally retarded. Also, 45.4 percent of the mothers who had IQ's below 80 accounted for 78.2 percent of the children with IQ's below 80. This laboratory survey is maintained on an ongoing basis, with the findings of individual studies of value to the retarded population, their families and public and private agencies serving the needs of this population.

In the area of training, 33 short-term courses attended by 2,332 trainees were sponsored by the three Mental Retardation Research and Training Centers. One center alone provided training for more than 600 rehabilitation counselors and special education personnel in specific rehabilitation techniques leading to employment of the retarded.

A continuing emphasis will be maintained by the three Mental Retardation Centers in 1970 on the departmental priorities of model cities, neighborhood service centers, motivating people to work, rural poverty, and other priority areas as they relate to mental retardation.

During the 1969 fiscal year, the Department of Health, Education, and Welfare appropriation to the three centers was $1,075,000.

3. Division of International Activities

The Division of International Activities is the focal point for the development of all SRS international activities. These include program operations in the fields of maternal and child health, services to crippled children, social welfare, and vocational rehabilitation of the physically handicapped and the mentally retarded. As part of a reorganization of August 1967, international staff of the Welfare Administration, Children's Bureau and the Vocational Rehabilitation Administration were brought together in one unit to administer programs designed to supplement and complement domestic programs and to strengthen relationships with other countries as well as to further U.S. foreign policy goals.

A major segment of the international program has been the development and support of cooperative research and demonstration projects in certain foreign countries.

This program, financed with U.S. owned foreign currencies derived from the sale of agricultural commodities, was initiated by the Vocational Rehabilitation Administration in 1961. A vital adjunct to these research activities is the interchange of experts program authorized under the International Health Research Act. As a result of this authority, the Social and Rehabilitation Service has arranged for the interchange of scientists and experts engaged in research between the U. S. and countries participating in this cooperative program.

Since the beginning of the research and demonstration program in 1961, 22 projects in various aspects of mental retardation have been approved by the Division of International Activities. The range of research interest is very broad encompassing both medical and non-medical projects as well as clients of all ages. Types of projects that are now in progress include: investigations concerning the incidence of phenylketonuria; experimentation with new techniques for training the mentally retarded; and investigations on the medical, psychological, social and cultural aspects of mental retardation. During the past year, projects dealing with mental retardation were approved in Celon, India, Israel, Poland and Tunisia.

The Administration on Aging

1. Older Americans Act - Title III Program

Title III of the Older Americans Act of 1965 provides for funds from the Administration on Aging to stimulate the establishment of a single agency in each State to be responsible for the coordination of all State activities and programs in aging. Once the governor has designated such an agency and the State plan has been approved, allotments are made to the State. The State, in turn, makes grants to public and nonprofit private agencies for (1) community planning and demonstration of programs in aging; (2) for demonstration of new programs or activities beneficial to older people; (3) training special personnel for such programs; and (4) establishment of new or expansion of existing programs, including senior centers.

Under a Title III grant, the Boulder River Junior Chamber of Commerce, in Boulder, Montana, is operating a project called "Senior Citizens Conducting Programs for the Mentally Retarded Aged." The program was initiated because existing services and programs at the Montana State Training School and Hospital were focused on younger residents and the older population was being neglected.

During the first year of the project six older people were trained to provide services to over 100 mentally retarded aged at the School. As a result 25 of these aged residents were placed in the community during the year, some in fulltime jobs and a few in nursing homes. During the second year, two additional older people were recruited and trained to work at the School and a part-time social worker was added to the project staff to help place and follow-up mentally retarded aged who return to their home communities. The project expects to return about 30 additional residents from the group to their communities by the end of the year.

2. Older Americans Act - Title IV Program

Title IV of the Older Americans Act authorizes the Administration on Aging to make direct grants or to contract for research and demonstration projects of national or regional interest and value. Under a Title IV grant to the Community Service Society of New York, a demonstration project is being conducted on

Staten Island in the recruitment, training, placement and retention of older people as volunteers in community service. Of the 256 volunteers, with an average age of almost 70, currently active in the program, 130 are serving at the Willowbrook State School, a 6,000-bed institution for the mentally retarded of all ages. Thirty-nine of the volunteers have been working at Willowbrook more than 2½ years.

Volunteers serve from 4 to 6 hours one or two days a week and perform such functions as feeding and playing with babies and young children, helping in the school rooms, and in the occupational therapy programs, sewing, stamping garments, and repairing toys and furniture in the shops. In addition, a group of women mend clothing for the School at the Stapleton Senior Center, and a folk dance group from another center visits the School once a week to teach dancing to teenage residents of a specially selected ward.

3. The Foster Grandparent Program

The Administration on Aging also administers the Foster Grandparent Program under contract with the Office of Economic Opportunity. The Foster Grandparent Program recruits and trains low-income men and women over 60 years of age to serve as foster grandparents to children in institutional and community settings. "Grandparents" provide two hours of individual attention to each of two children daily, and usually work five days a week.

In December 1968, there were 68 projects in 40 States and Puerto Rico. About 8,000 children--5,500 of whom are mentally retarded--in 203 institutional and community settings are served by 4,000 foster grandparents. Over 120 communities are affected by the program and many more have expressed interest in developing a project.

The work of the foster grandparents is entirely child-related, on a one-to-one basis, and aimed at providing personal attention to neglected and deprived children, not to relieve institution staff of routine care tasks. Administrative staff of institutions for the mentally retarded report that the children show improvement in self-care skills and motor skills and that, in addition, the positive results which the children show often serve to raise the morale of the institution staff.

There have been quite a few evaluations of individual Foster Grandparent projects within the past two years. All of them conclude that, based on the project studied, the program is a viable one which has great potential for further expansion and growth. The report of the findings of a two-year study of the program at the Denton State School, Denton, Texas, conducted by Dr. Hiram J. Friedsam and Mr. H.R. Dick, North Texas State University, concludes:

> "No matter how fleeting the contact or how limited the carryover, the program does enrich the lives of the children it touches, and anyone who is familiar with institutions for retarded children will not judge this to be a minor success."

In one project for retarded children, seven children achieved the level of functioning that enabled them to enter Head Start classes; four were admitted to special education classes; one boy thought to be retarded was enrolled in summer Head Start and then registered for a regular classroom program. In another project, "Grandparents" are working within a public school, enabling retarded children to attend regular classes.

Grandparents are forming a link between the community and the institutions, bringing the outside in to the children and bringing to the community a new attitude on the subject of mental retardation.

Further information may be obtained from the Commissioner, Administration on Aging, Social and Rehabilitation Service, Department of Health, Education, and Welfare, Washington, D.C. 20201, or the Office of Older Persons Programs, Office of Economic Opportunity, Washington, D.C. 20506.

Children's Bureau

Introduction

The concern of the Children's Bureau for mentally retarded children and their families stems initially from its responsibility under the Basic Act of 1912 to "investigate and report on all matters pertaining to the welfare of children and child life." In the first 6 years of its existence, three of the major studies produced by the Bureau dealt with mental retardation.

The passage of the Social Security Act in 1935 and the assignment to the Bureau of the added responsibility of administering Federal grants for maternal and child health, crippled children, and child welfare services, emphasized the principle that all of the people, through the Federal government, share with the State and local governments responsibility for helping to provide community services that children need to have for a good start in life. The Social Security Act also afforded the Bureau an opportunity to help the States develop demonstrations and special programs in areas where there were gaps in services.

As recently as 1954, maternal and child health activities in the Children's Bureau on behalf of mentally retarded children and their families were extremely limited. Many local public health nurses were reporting suspected mentally retarded children in their caseloads, but for the most part, they had few or no resources for establishing a diagnosis. By age groups, the greatest gap in available services was in relation to infants and preschool children. It appeared that many of the services that were lacking could best be provided through program emphasis within the framework of the maternal and child health program. The basic interests of this program - that is, preventive health services, child health supervision, growth and development and the fostering of good parent-child relationships - are also the basic interests of a program for mentally retarded children.

It was on this basis and to achieve these goals that the Congress for fiscal year 1957, increased the Children's Bureau's annual maternal and child health appropriation and earmarked $1 million specifically for special projects serving this group of children. The Appropriations Committee also expressed the hope that an additional million dollars of the increase, which was to be distributed to the States on a regular formula basis, would be used to implement services for the mentally retarded. The enactment of P.L. 88-156 in 1963 increased the authorization and has resulted in increased appropriations both for special projects for mentally retarded children and in the amount of regular formula funds designated for this purpose. P.L. 89-97, "Social Security Amendments of 1965," made further improvements, including the provision of grants for the training of professional health personnel to work with crippled children, particularly the mentally retarded and those with multiple handicaps.

P.L. 89-97 also made available project grants to provide comprehensive health care and services for children and youth of preschool or school age, particularly in areas with concentration of low-income families. The appropriation for the fiscal year 1966 for this program was $15 million; for fiscal year 1967 $35 million; for fiscal year 1968 $37 million; and for fiscal year 1969 $39 million.

Mentally retarded children and their families are also aided by the Children's Bureau's program of child welfare services. The goal of this program is the provision of "public social services which supplement, or substitute for, parental care and supervision for the purpose of (1) preventing or remedying, or assisting in the solution of problems which may result in, the neglect, abuse, exploitation, or delinquency of children, (2) protecting and caring for homeless, dependent or neglected children, (3) protecting and promoting the welfare of children of working mothers, and (4) otherwise protecting and promoting the welfare of children, including the strengthening of their own homes where possible, or, where needed, the provision of adequate care of children away from their homes in foster family homes or day-care or other child-care facilities." The States used grant-in-aid funds for child welfare services, authorized by the Social Security Act, early in scattered instances to provide services in behalf of retarded children, including foster care, and for child welfare workers who gave some service to this special group of children. It was not until 1957, however, that special child welfare staff was provided by the Children's Bureau to assist the States in providing services to these children. The years since, as part of the Bureau's overall effort to reach out to special groups of children, have seen substantially increased child welfare services extended to the mentally retarded. Although programs for the mentally retarded have developed markedly, a considerable need for service to this group remains.

A further impetus to improving care of retarded children was provided by the Child Welfare Research and Demonstration Grants Program authorized by the Social Security Amendments of 1960 and by the Maternal and Child Health and Crippled Children's Services Research Projects authorized by the 1963 amendments. Some of the program research conducted under both of these programs pertains to mentally retarded children.

The Child Health Act of 1967, which is included in P.L. 90-248, the "Social Security Amendments of 1967," makes provision for the following: (1) increased authorizations for child health under Title V; (2) services for reducing infant mortality and otherwise promoting the health of mothers and children; (3) family planning services; (4) continuation of the programs of maternity and infant care project grants and of comprehensive grants for the health of preschool and school-age children; (5) new dental health service projects; (6) emphasis on early identification of health defects of children; and (7) broadening the scope of research and training authorizations. Reducing the incidence of mental retardation and improving care to mentally retarded children are among the objectives of these provisions.

The "Social Security Amendments of 1967" authorize grants to States for services to families and children receiving Aid to Families with Dependent Children (AFDC). Based on each such family's special circumstances and requirements, services are provided for assisting the family to obtain or retain capability for self-support and care, maintain and strengthen family life and foster child development. Handicapped children and their families receiving AFDC are included in this program.

I. Preventive Services

A. Maternity and Infant Care Projects

The report of the President's Panel on Mental Retardation emphasized the interrelationships of lack of prenatal care, prematurity, and mental retardation. A recent major emphasis in Children's Bureau programs has been the Maternity and Infant Care Projects, authorized by P.L. 88-156, "Maternal and Child Health and Mental Retardation Planning Amendments of 1963." This law provides for a new authorization for project grants to meet up to 75 percent of the cost of projects for the provision of necessary health care to prospective mothers who have, or who are likely to have, conditions associated with childbearing which increase the hazards to the health of the mothers or their infants, and whom the State or local health department determines will not receive necessary health care because they are from low-income families or for other reasons beyond their control. In addition, the legislation provides for medical and hospital care for premature infants and other infants at risk. Late in fiscal year 1964, $5 million was appropriated for this program, and eight projects were approved. For fiscal year 1965, $15 million was appropriated; for fiscal year 1966, $30 million, for fiscal year 1967, $30 million; for fiscal year 1968, $30 million, and for fiscal year 1969, $36 million. By the end of December 1968, 53 projects were in operation.

P.L. 90-248 extends the program of maternity and infant care projects until June 30, 1972, after which they become a special part of each State health services plan. The new legislation continues the intent to help reduce the incidence of mental retardation and other handicapping conditions caused by complications associated with childbearing, and in addition calls for services for helping to reduce infant and maternal mortality. It also adds authority for projects for intensive care of infants and for family planning services.

B. Phenylketonuria and Other Metabolic Diseases

A second major emphasis in prevention within the past few years has been in relation to phenylketonuria (PKU). This inborn error of metabolism has in the past been responsible for one percent of the population in our State institutions for the mentally retarded. By detecting families with the condition and by placing young infants with the condition on a special diet, mental retardation can usually be prevented. The Children's Bureau had been working with State health departments in developing and trying out various screening and detection programs, developing the necessary laboratory facilities, and assisting States in providing the special diet and follow-up programs for these families. When the Guthrie inhibition assay method for screening newborn babies was developed, the Children's Bureau supported field trials of this test. More than 400,000 newborn babies in 29 States were screened, and 39 cases of PKU were found, an incidence of almost one in 10,000.

The Children's Bureau is now urging that all States have a program for screening infants for PKU. Although such a program may be initiated without a legislative requirement, in many States laws have been enacted on this subject. As of the end of December 1968, 43 States had such laws, most of them making screening for PKU mandatory. The 43 States are:

Alabama
Alaska
Arkansas
California
Colorado
Connecticut
Florida
Georgia
Hawaii
Idaho
Illinois
Indiana
Iowa
Kansas
Kentucky
Louisiana
Maine
Maryland
Massachusetts
Michigan
Minnesota
Missouri
Montana
Nebraska
Nevada
New Hampshire
New Jersey
New Mexico
New York
North Dakota
Ohio
Oklahoma
Oregon
Pennsylvania
Rhode Island
South Carolina
Tennessee
Texas
Utah
Virginia
Washington
West Virginia
Wisconsin

As more children with PKU are found, the problems relating to treatment services are receiving increased attention. Funds were granted for planning a 5-year collaborative study of treated phenylketonuric children, for purposes of increasing knowledge of methods of treatment of children with this disease; this study is now under way, with a number of clinics participating. A grant has also been made to develop a reference and standard service for phenylalanine determinations needed in screening and treatment. In April 1966, an important meeting was financed by the Children's Bureau to discuss PKU screening and treatment problems, pathogenesis of the disease, and other relevant topics. The proceedings of this Conference have been published under the title, "Phenylketonuria and Allied Metabolic Diseases." "Recommended Guidelines for PKU Programs" have also been prepared to make known the Children's Bureau recommendations for a comprehensive PKU program.

Interest is also increasing in metabolic diseases other than PKU that lead to mental retardation. The Children's Bureau is continuing to support a study of the clinical application of screening tests to detect galactosemia, maple syrup urine disease, and histidinemia. Also, support is being given to studies of new approaches to broader screening methods; for example, support is being given to a study which would make available a battery of automated tests for screening metabolic diseases. In addition, field trials are being conducted of a simple method to determine elevations of 10 different amino acids, for detection of metabolic disorders.

C. Lead Poisoning

In the area of prevention, increasing attention is being paid to lead poisoning. Despite present-day manufacture and use of lead-free paint, many children become mentally retarded or suffer other damage from ingestion of chips of lead-containing paint from walls and woodwork in old, dilapidated housing. A publication, "Lead Poisoning in Children," addressed to public health workers, has been prepared, suggesting a program of prevention, casefinding, follow-up of cases, and other measures to cope with this problem. Some of the Children and Youth projects have had a special interest in finding and treating children with lead poisoning.

D. Immunizations

From experience with immunization of children against diphtheria, tetanus, and pertussis, and against measles, it has been learned that special efforts need to be made to reach children in the low-income neighborhoods of many cities. To achieve the maximum effect when the rubella vaccine is licensed, therefore, a major public health program will have to be launched. As a first step in this direction, the Children's Bureau prepared and distributed a brochure on the subject of Rubella.

E. Familial Mental Retardation

Interest is increasing in mental retardation associated with poverty. The Children's Bureau has published "Children of Deprivation," a report of a project at the University of Iowa dealing with this problem, and some of the Children's Bureau-supported mental retardation clinics are now showing more active concern with this cause of mental retardation.

II. Basic and Supportive Services

A. Casefinding and Screening

The Children's Bureau has, from the beginning of its work in financing programs for retarded children, emphasized the importance of early detection and casefinding. Preference to young children as new cases has been encouraged in the clinics supported by Children's Bureau funds. In recent years training, particularly for nurses, has emphasized the skills necessary for early detection. "A Developmental Approach to Casefinding with Special Reference to Cerebral Palsy, Mental Retardation, and Related Disorders," written by a nurse, was published in 1967 to provide a tool for developing such competency.

B. Clinical Services

Support of clinical services for mentally retarded children is one of the most important uses for Children's Bureau mental retardation funds. The services provided include diagnosis, evaluation of a child's capacity for growth, the development of a treatment and management plan, interpretation of findings to parents and follow-up care and supervision. As of the end of November 1966, of the almost 200 mental retardation clinics in the country, the staff and services of 135 were supported in whole or in part by Children's Bureau funds. The Children's Bureau-supported clinics served approximately 40,000 children in fiscal year 1966. Somewhat over one-third of the children new to the program were under 5 years of age. During fiscal year 1967 and 1968, the number of Children's Bureau-supported clinics increased; by the end of fiscal year 1968 there were 150 such clinics serving approximately 43,000 children. The total number of mental retardation clinics in the United States is now 235.

The Children and Youth projects authorized by P.L. 89-97 offer an opportunity for providing increased services to mentally retarded children in the areas served by the projects. As of the end of December 1968, 58 Children and Youth projects were in operation. These projects provide comprehensive health services for children especially those living in areas with concentrations of low-income families.

C. Crippled Children's Services

Since enactment of the Social Security Act in 1935, the Federal government, through the Children's Bureau, has assisted the States in providing services to crippled children. Although exact data are not available, it is known that relatively few mentally retarded children were cared for in these programs prior to 1963. The enactment of P.L. 88-156, providing for increased funds for the crippled children's program and for the earmarking of some of the funds specifically for mentally retarded children, has resulted in more attention being paid to physically handicapped retarded children. In some States, the definition of crippling conditions is being broadened to include conditions for which services had not hitherto been given. Some children who would formerly have been turned away are now being given services.

An important use of the expanded funds available for mentally retarded crippled children is in providing services for institutionalized children; for example, orthopedic services not hitherto available to these children. In addition, the Children's Bureau staff itself has provided some consultation to the institutions, particularly in the fields of nutrition and physical therapy and to some extent in nursing.

A recent development has been a broadening of the scope of services to give more attention to children who are both physically handicapped and mentally retarded, children who have several physical handicaps, and children with serious learning disorders. Some mental retardation clinics are showing increased interest in serving these children and a number of special clinics, financed by Children's Bureau funds, have been set up.

Another use of Crippled Children's funds in the mental retardation field is a study and demonstration project now under way concerning the speech and language skills of mentally retarded children.

In 1966, over 20,000 children with diagnoses of various forms of mental retardation received medical services in the Crippled Children's program. The 1967 amendments to the Social Security Act require that State plans for Crippled Children's services provide for more vigorous efforts to screen and treat children with disabling conditions. This provision should result in an increase in the number of mentally retarded children identified and treated.

D. Cytogenetic and Biochemical Laboratory Programs

A new use to which some of the Children's Bureau funds earmarked for mental retardation are being put is in the area of cytogenetic and biochemical laboratory services. Project grants have been approved which establish such programs as extensions of clinical services at hospitals or medical schools. Projects include chromosome analysis and diagnosis of various medical conditions which may be genetic and result in mental retardation. On the basis of these analyses, counseling may also be given to parents seeking advice on genetic questions. The biochemical laboratories may also do continuing monitoring of patients with metabolic diseases. Training in medical genetics is also an important aspect of many of these projects. By the end of December 1968, 20 such projects had been approved. In March 1966 a group of experts in this field was called in to discuss and make recommendations on present and future Bureau programs in this area.

E. Dental Programs

Programs for the dental care of handicapped children, including the mentally retarded, have been encouraged in the past; but dental care will be given new support as a result of the 1967 Social Security Amendments. These amendments authorize support of up to 75 percent of the cost of projects to provide comprehensive dental health services for children from low-income families. No appropriation for this program was made for fiscal year 1969.

F. Family and Child Welfare Services

The Children's Bureau administers child welfare services funds authorized by the Social Security Act, as amended, for the purpose of cooperating with State public welfare agencies in establishing, extending and strengthening child welfare services. These funds are allocated to States on a formula basis. The appropriation for fiscal year 1969 was $46 million. Although none of these funds are earmarked especially for serving the retarded, mentally retarded children are provided these services. Child welfare services, which can benefit the mentally retarded and their families, include parent counseling, homemaker services, day care services, foster family care, care in group homes, adoption services, services to unmarried mothers, and certain institutional pre-admission and aftercare services.

At the present time, all State public welfare programs provide some child welfare services for mentally retarded children. By conservative estimates of the Children's Bureau, 45,000 mentally retarded children receive child welfare services from public welfare agencies.

The "Social Security Amendments of 1967" authorize grants to State public welfare agencies for providing services to families and children receiving Aid to Families with Dependent Children. Federal funds are authorized to pay 85 percent of State costs for these services through fiscal year 1969. After July 1, 1969, Federal funds are authorized to pay for 75 percent of State costs. This program, also administered by the Children's Bureau, will bring increased attention to the

the special needs of the estimated 131,000 AFDC children who are mentally retarded and to the family conditions in which mental retardation is often rooted.

Following are examples of developments related to the extension and improvement of family and child welfare services to mentally retarded children and their families:

A mental retardation specialist, during the two years since he was first employed by a State public welfare agency, has contributed substantially to the development of services and facilities, including specialized foster family care, from which retarded children and their families benefit. In addition, he has been instrumental in improving coordination among the State's programs for the retarded.

A State on the basis of its experience in providing the range of child welfare services through a special unit for the retarded in one locality, is now extending increased child welfare services to retarded children and their families in other areas of the State. In another State, the school of social work has a mental retardation field instruction unit located in a county public welfare department. According to the director of the county agency, this unit, which receives Children's Bureau support, benefits the county in addition to providing a learning experience to the students. Increased services rendered by the students to the county's mentally retarded and their families is one benefit. The director also points out that the unit's emphasis on problems connected with mental retardation has served to "sharpen up all the (agency's) workers to give this particular problem more attention."

Several States report that with the support of a child welfare worker and assistance provided through this service in utilizing other community resources, parents often are able to keep their retarded children at home and keep their families intact. One agency through group counseling has assisted parents not only to meet the needs of their retarded children better but also to take action aimed at development of additional community programs for the retarded.

Another State public welfare agency describes its new homemaker service project as a "real success." This project provides 32 itinerant homemakers who specialize in serving families of retarded children. Through homemaker services, an overburdened mother can be relieved of the constant and full responsibility for the day-to-day care of her retarded child. Frequently, she acquires new skills which help her in better home management and in her special problems with child care.

Another important service provided by several State public welfare agencies to assist mentally retarded children and their families is day care service. Day care services offer both constructive experiences for some retarded children and necessary help and relief for their parents. This service often may be the key factor in determining whether a child can remain with his family. In one State, the number of licensed daytime activity centers for the retarded has quadrupled, from 21 to more than 80, in about a four-year period. The State child welfare agency licenses these centers. With concern for quality in their day care programs for the retarded, some States have given special attention to the development of standards and to training of day care personnel. The value of stronger linkage between the day care center and the family is also receiving increased attention in many of these programs. During the past year, Children's Bureau has cooperated with the National Association for Retarded Children (NARC) in planning and conducting a workshop on day care services, held in advance of the NARC Annual Convention. The general purpose of the workshop was to assist in the development and improvement of day care services for the retarded.

Most States provide some foster family care for retarded children. In all, it is estimated that 14,000 of the retarded children receiving public child welfare services are in foster family care.

Some children, who must be cared for outside their own homes, can profit from close interpersonal relationships and respond to the stimulation of foster family life. Short-term foster care at intervals or during period of crisis may enable a retarded child's family to provide adequately for him at home for the most part. For other retarded children, foster family care permits long-term benefits of family life and community living. Foster family care would be the plan of choice for many children who have been placed inappropriately in large residential facilities. In fact, some States are giving attention to the "exchange" of children between institutional and child welfare services programs to assure more appropriate services for particular children.

The experience of several States illustrates that retarded children can profit from adoption and that adoptive placement is feasible for many of these children. An article by the Children's Bureau specialist on adoptions and services to unmarried mothers, "The Adoption of Mentally Retarded Children," was published in the January-February 1968, issue of CHILDREN. As some evidence of the interest in adoption of the retarded, over 8,000 reprints of this article have been disseminated, a large portion of this number upon request.

Family and child welfare services also may have preventive aspects in relation to mental retardation. For example, day care or foster care for children from certain deprived homes may be preventive services.

Homemaker service may be preventive in nature when brought into play with some expectant mothers who need relief from the physical demands of caring for other children. Protective services can reduce child abuse as a cause of mental retardation. Services to unmarried expectant mothers can assure utilization of proper prenatal services.

Family and child welfare workers also are in a key position with regard to early casefinding, assistance with obtaining proper diagnosis and providing continuity of planning and services consistent with the needs of the individual retarded child and his family.

In spite of the efforts and potential of family and child welfare services, which have been cited, numbers of retarded children and their families need and could profit from such services not now available. Professionally skilled staff, new programs, and extension of those in existence are needed. The continuing emphasis on community services as a means of combating mental retardation will place increasing demands on family and child welfare agencies. The need for increasing these services of the public welfare agencies is expressly emphasized by the report of the President's Committee on Mental Retardation, MR 68, The Edge of Change.

G. Program Aids

The Children's Bureau has assisted in the production and circulation of films on mental retardation and has also operated an exchange of educational materials as a service to the mental retardation clinics. Since November of 1961, through this exchange, well over 400 items have been distributed to each of the mental retardation clinics in the country. Special publications have been developed which have been in great demand. In addition, pertinent articles appearing in various professional journals have been reprinted and distributed. During the calendar year 196[illegible], more than 29,000 individual copies of publications were distributed in response to requests. A recent publication, "Selected Reading Suggestions for Parents of Mentally Retarded Children" has been very much in demand. Another new publication, "Feeding the Child with a Handicap" has also been popular.

III. Training of Personnel

A. Training for Health Services

Training activities for health services in the field of mental retardation, assisted by Children's Bureau funds, have encompassed many approaches: Grants for fellowships; support of and participation in institutes, conferences, and other short-term training sessions; consultation on course curricula; arrangements for clinical experience in mental retardation clinics; distribution of informational materials to professional workers; and recently support of the university-affiliated centers being constructed under authority of P.L. 88-164, Title I, Part B.

The following points up the wide range of disciplines involved in training activities and illustrates the variety of training approaches.

During fiscal year 1965, the Children's Bureau funded 27 pediatric fellowships in mental retardation; in fiscal year 1966, 39; and in fiscal year 1967, 26 such fellowships were funded. In nursing, assistance was given in fiscal year 1967 and continued in 1968 to 10 university schools of nursing for their graduate programs in maternal and child nursing, including mental retardation; in these programs special attention is given to the nursing role in casefinding, prevention and intervention. In addition, in both years four of these university schools of nursing were given grants for continuing education courses for nurses in mental retardation. State agencies also sponsored short-term, intensive educational programs in mental retardation for staff nurses. The Fourth National Workshop for Nurses in Mental Retardation sponsored by the Children's Bureau, held in Miami in 1967, was attended by 60 nurses.

At the University of Washington in Seattle, and at the University of Tennessee in Memphis, the Children's Bureau is supporting training programs for nutritionists in mental retardation and handicapping conditions. In the 1967-1968 academic year, eight nutritionists were enrolled for the three-month fellowship at the University of Washington, and one for the 18 months' program leading to a Master's degree. In 1968 staff discussed training programs in mental retardation at a Symposium for Research and Therapeutic Dietitians sponsored by Walter Reed Hospital, Washington, D.C., and at a major session of the Annual Meeting of the American Dietetic Association in San Francisco. About 450 dietitians were reached through these two meetings.

In the 1966-67 academic year, 45 pre-masters social work students received their training in 19 Children's Bureau-supported mental retardation clinics from 20 graduate schools of social work; some of these students received stipends through training projects supported by the Children's Bureau. During 1967-68, 59 students from 19 schools of social work, received their training in 22 such clinics. Additional students were placed in Children's Bureau-supported programs where they could have experience with mental retardation cases; there were 90 students from 18 schools of social work in improving Maternal and Child Health and Crippled Children's Services, with additional students placed in other Children's Bureau-supported projects. A small number of post-masters social work students, who are receiving stipends through Children's Bureau projects, received exposure to mental retardation in their field placements.

Training of dentists to work with mentally retarded children was stimulated, as was the training of psychologists, occupational therapists and physical therapists. In the latter two fields, special project grants to the University of Florida for occupational therapy and the University of North Carolina for physical therapy, to enhance the preparation of therapists for service to multihandicapped children, are in their third year of development. In occupational therapy, grants to Boston University and the University of Southern California are facilitating the development of graduate programs with emphasis on evaluation of and programming for handicapped children including the mentally retarded. During 1968, the proceedings of two seminars for occupational therapists on perceptual-motor dysfunction were reprinted and widely distributed. Staff members in both disciplines are being added to increasing numbers of university-affiliated facilities to expand the training of future therapists, in an interdisciplinary setting, for service to mentally retarded children and their families.

Children's Bureau special project funds support academic training in speech pathology and audiology in 5 universities, both for faculty and for stipends to 31 students seeking an M.A. or Ph.D. degree. Another university training program in communicative disorders supports faculty in pediatrics and otolaryngology as well as in audiology and speech pathology. A clinical fellowship program in pediatric-audiology has been expanded from 1 to 3 universities. All these training programs include a mental retardation component.

Medical genetics represents a new field of training which was begun in fiscal year 1965 and extended in subsequent fiscal years. Training programs, as part of the cytogenetic and biochemical laboratories, were set up for physicians and biochemists to specialize in aspects of medical genetics, particularly in cytogenetics, metabolic disease, and endocrinology.

The 1965 amendments to the Social Security Act made additional provision for grants for training purposes to be administered by the Children's Bureau. The amendments authorized appropriations for grants to be made to public or other nonprofit institutions of higher learning "for training professional personnel for health and related care of crippled children, particularly mentally retarded children and children with multiple handicaps." The amounts appropriated for this program, $4 million in fiscal year 1967 and $7 million in fiscal year 1968, were used primarily to support training in the university-affiliated centers for diagnosis and treatment of the mentally retarded. For the fiscal year 1969, $9 million was appropriated for this program.

The new Section 511 of the Social Security Act as amended in 1967 replaces and expands the training authority to include all personnel involved in providing health care and related services to mothers and children, with special attention to undergraduate training. This amount, supplemented by special project funds from the MCH and CC programs, was used primarily to develop and support programs of interdisciplinary training in 22 universities. These university-affiliated programs are developing a variety of training approaches for the many disciplines involved in caring for the retarded child.

B. Training for Child Welfare Services

States are urged to provide educational leave for the training of child welfare staff. Grant-in-aid funds may be used for this purpose. All States have structures for a staff development program, including orientation, inservice training, and educational leave. These programs contribute to the overall increase of child welfare staff which is better able to serve the mentally retarded.

The 1962 Amendments of the Social Security Act provided a new avenue for augmenting the supply of trained child welfare workers by establishing grants for child welfare training projects. This program provides grants to public and other nonprofit institutions of higher learning for special projects for training personnel in the field of child welfare, including traineeships to students. Training for child welfare services to the mentally retarded and their families is included in this program.

While facts on this program are not available for the current academic year, during the 1967-68 school year five projects were funded to provide social work field instruction units in mental retardation settings. Thirty students were trained in the five units. Twenty-nine students receiving child welfare traineeships through this program were also placed in mental retardation settings by 19 schools of social work. For that academic year, also, information from schools of social work indicates that more than 75 child welfare-related mental retardation agencies were providing field instruction experience for over 200 students.

One State in cooperation with a school of social work completed a project for the training of foster parents of the mentally retarded during 1968. A total of 71 foster parents registered for this training project which was supported by a child welfare training grant from the Children's Bureau. Over 400 copies of the final report of the project were disseminated to schools of social work, State departments of public welfare, and other interested individuals.

IV. Research

The Children's Bureau Clearinghouse, which maintains an inventory of current research relating to children, recently revised its publication, "Research Relating to Mentally Retarded Children"; this is a listing of the mental retardation studies reported to the Clearinghouse during the period 1949-1965, including references to published reports.

Two research grant programs administered by the Children's Bureau can be used for program research assisting mentally retarded children:

A. Child Welfare Research and Demonstration Grants Program

The Child Welfare Research and Demonstration Grants Program, authorized by the Social Security Amendments of 1960, provides financial support for special research or demonstration projects in child welfare which are of regional or national significance, and for special demonstrations of new methods or facilities which show promise of substantial contribution to the advancement of child welfare.

Since community support is vital to improvement of child welfare services, an important function of several projects is to develop support through interpretation and communication of the problems that many children face, ranging from shattered families to mental retardation.

Projects relating to mental retardation which have been completed include: (1) a demonstration to test the feasibility and value of foster home care for deprived mentally retarded children; (2) a demonstration, training, and service project designed to test the feasibility of training and using unskilled personnel as aides to professional personnel in caring for retarded children in the areas of homemaking and child care, physical medicine and nursing care, speech therapy, play activity, and auxiliary maternal care; (3) a study of specialized foster home care for deprived mentally retarded children; and (4) a study of existing laws and their administration applicable to children suffering from mental disorders, including their commitment, care, and guardianship.

A grant was made to Howard University for a project to determine how much a day-care program, plus parent education activities, can accomplish to offset intellectual and social disadvantages encountered by environmentally deprived children on entering public school. The research component of the project was carried out by the Children's Bureau. Recently, the entire project was transferred to George Washington University.

During fiscal year 1969, the Child Welfare Research and Demonstration Grants Program will be supporting 8 other projects with mental retardation elements. Three are day-care centers which attempt to develop techniques for supplementing the early experience of underprivileged children. These centers are located at Syracuse University, University of North Carolina, and at Cambridge, Massachusetts. The latter is sponsored by the KLH Corporation, and is an attempt to evaluate the feasibility of combining Federal and industrial funds in such a venture. Another grant is to the School of Applied Social Sciences at Case Western Reserve University to run a neighborhood multi-service center. One project deals with abused and neglected children, another with law, mental disorders and juvenile processes. The last two studies relate to work with infants and preschoolers who are prone to become mentally retarded with reasons other than genetic or congenital factors. As the vast majority of mentally retarded children appear to have functional retardation an increased effort has been launched to develop feasible programs of prevention. A study with the Family Service Association of Nassau County is aiding the cognitive growth and development of preschool children using a special day-care program combined with work with parents. At the University of Florida a special study is focusing on using child development aides who teach mothers how to stimulate and motivate their infants and toddlers without the necessity of placing them in a day-care group program.

B. Maternal and Child Health and Crippled Children's Services

The purpose of this research grant program, authorized by the Maternal and Child Health and Mental Retardation Planning Amendments of 1963, is to support studies that show promise of making a substantial contribution to the advancement of health programs for mothers and children. Programs for mentally retarded children may be included in these studies.

In the area of mental retardation, projects have been funded which will study ways to improve amounts and quality of prenatal care. These are an effort to reduce the occurrence of prematurity and as a means of preventing mental retardation due to these causes. Several projects supported in various schools of medicine have as their objective an evaluation of methods for screening children for metabolic and other inherited diseases which can lead to mental retardation. They also seek to develop procedures for screening preschool children for neurological damage and psychological deviancy.

In one project, a major step may be achieved in alleviating the critical shortage of trained professional psychologists. This project will test, in selected mental retardation clinics throughout the country, a plan for utilizing nonprofessional personnel. Another major study that has been funded proposes to uncover every case of mental retardation in a well-defined population. The prevalence of mental retardation and its relation to social, economic, and demographic characteristics of the individual and his household will be investigated in the hope of uncovering etiological relationships.

The final report of a study entitled "Medical Needs of Children in Institutions for the Mentally Retarded" makes clear that some State institutions are failing to provide the necessary services to meet the health and medical needs of the mentally retarded child. Suggestions are made to correct this long-standing problem using the financial resources of the State and the medical personnel in the local community.

The Retarded Infants Service of New York has completed its report entitled "Feasibility of Training and Using Unskilled Personnel as Aides to Professional

Personnel in Caring for Retarded Children." This study is a pioneering effort in using aides in a variety of service programs concerned with mentally retarded children and has wide applicability. Still another study examines intensively the sequelae of infants and toddlers with congenital rubella and another study will follow up low birth-weight infants.

During fiscal year 1969, the Maternal and Child Health and Crippled Children's Services Research Grants Program will be supporting 10 projects with mental retardation elements or components. One new study will undertake the treatment of serotonin deficiency in children with Down's Syndrome.

The "Social Security Amendments of 1967" provide that after June 30, 1968, special emphasis shall be given to research projects which will study need for, feasibility, costs and effectiveness of use of health personnel with varying levels of training.

Medical Services Administration

The Medical Services Administration (MSA) is the agency responsible for the administration of Title XIX of the Social Security Act.

The Mental Health Branch, Health Services Division, MSA, has the responsibility for the mental retardation activities in conjunction with the medical assistance program.

The mentally retarded who meet a State's eligibility requirements for the medical assistance program may receive the same benefits in terms of medical care, as any other recipient. The amount and scope of medical services depend on the individual State plan.

The mentally retarded who are determined eligible may also benefit from the Social Security Amendment of 1967, under assistance in the form of institutional services in Intermediate Care Facilities.

During the fiscal year July 1, 1967, to June 30, 1968, approximately $30,000,000 in Federal funds was awarded to 5 States through Title XIX for payment of medical services and skilled nursing services provided to the mentally retarded. Those States receiving assistance were: Pennsylvania, Wisconsin, Texas, Kansas and Oklahoma.

Rehabilitation Services Administration

Introduction

The Rehabilitation Services Administration is responsible for a broad range of programs designed both for the provision of diagnostic, treatment, and rehabilitation services for the mentally retarded, and for the support of special facilities and activities to expand and improve national resources for serving the mentally retarded. These programs include the State-Federal vocational rehabilitation program, as well as special project grants for the expansion and innovation of vocational rehabilitation services; the improvement of State residential institutions and sheltered workshops for the mentally retarded; the planning and construction of rehabilitation facilities and sheltered workshops, the construction and staffing of specialized community facilities, and the construction of university affiliated facilities for the mentally retarded; and training for professional, supportive and technical personnel already engaged or preparing to engage in occupations in the care and rehabilitation of the mentally retarded.

These diverse activities are unified by the common goal and objective of assisting mentally retarded individuals to achieve and maintain the maximum personal, social, and economic competence of which they are capable. Underlying these activities is the continuing concern for expanding the opportunities and resources available to the more severely mentally retarded.

I. Basic and Supportive Services

A. Vocational Rehabilitation Services

Under the public rehabilitation program, grants are made to State vocational rehabilitation agencies to assist them in providing rehabilitation services to mentally and physically disabled individuals who have substantial employment handicaps and who can reasonably be expected to be rehabilitated into gainful employment. Among the services provided by State vocational rehabilitation agencies are comprehensive medical, psychosocial and vocational evaluation; physical restoration; counseling; adjustment, pre-vocational and vocational training; maintenance and transportation during the rehabilitation process; placement in suitable employment; services to families of handicapped people when such services contribute substantially to the rehabilitation of the handicapped client; recruitment and training services to provide new careers for handicapped people in the field of rehabilitation and other public service areas; and follow-up services to assist handicapped individuals to maintain their employment.

Of the 207,918 disabled people rehabilitated through the State-Federal program in fiscal year 1968, approximately 19,100 were characterized by the primary disability of mental retardation. Looking ahead, it is projected that about 26,000 retardates will be rehabilitated through the public program in fiscal year 1969.

There are many ways in which State vocational rehabilitation agencies have been organizing and developing their services for the mentally retarded. Basic to the vocational rehabilitation effort has been the growing reliance on counselors and other vocational rehabilitation staff who work only with retarded clients. This specialized staff may be assigned to local vocational rehabilitation offices, schools, institutions, sheltered workshops, or other facilities serving the mentally retarded. By concentrating their attention on the mentally retarded clients, these counselors are successfully developing rehabilitation plans based on the special problems of the retarded and are able to be broadly responsive to the needs of both the client and his family. As special vocational rehabilitation programs and facilities for the retarded continue to be developed and expanded, the number of specialized counselors within State vocational rehabilitation agencies continue to increase.

The specialized vocational rehabilitation staff working with the mentally retarded has been particularly effective in the development of cooperative vocational rehabilitation-school programs designed to assist the retarded young person to make a satisfying transition from school to work. These cooperative school programs are found in many communities throughout the country and have greatly strengthened both special education and vocational rehabilitation efforts with the mentally retarded. The cooperative program structure varies from State to State, and the variety of approaches is extraordinary. In some States, program administration is Statewide and in others there are individual agreements with individual school districts. Some programs function only to serve the mentally retarded and others include youth with all kinds of disabilities. In some States, only vocational rehabilitation and special education are administratively involved, while in others representation includes vocational education.

Most cooperative arrangements have brought about the development of vocationally oriented curricula within the schools. All of them, however, provide for a comprehensive evaluation of the retarded young person's vocational rehabilitation potential; the provision of personal adjustment and pre-vocational training; counseling; on-the-job training and work experience; job placement, follow-up and related vocational rehabilitation case services.

The number of retarded young people enrolled in cooperative vocational rehabilitation work-study programs is increasing steadily as new programs are developed. An estimated 6,600 are enrolled in Florida; 4,180 in Texas; 3,960 in Georgia; and 3,300 in California. These cooperative programs have proven themselves effective in reducing the school dropout rate of retarded youngsters and have provided a technique for continuous service to youngsters during the school years when they are best able to benefit from them.

Another emphasis of State vocational rehabilitation agencies has been the establishment of rehabilitation facilities, such as comprehensive rehabilitation centers, evaluation centers, occupational training centers, workshops, half-way houses, and other specialized facilities serving the mentally retarded. Such rehabilitation facilities may be established by State rehabilitation agencies, by the State agency in cooperation with other public agencies, or by other public or private agencies.

State vocational rehabilitation agencies may assist in the construction of rehabilitation facilities in a variety of ways. They may construct new buildings; alter, expand or renovate existing buildings; purchase necessary equipment; and provide initial staffing support for a period of 4 years and 3 months. In some cases, State agencies provide direct grants to the facilities from State appropriated funds. In other cases, local facilities and workshops are supported by means of private contributions which may be used for Federal matching.

The rehabilitation of the mentally retarded is a major concern of the State agencies and this concern is evidenced both in programs directed specifically at serving the retarded and in programs in which the retarded are served in addition to other special groups of individuals. Projects for groups, such as Selective Service rejectees, welfare clients, public offenders and the economically disadvantaged have demonstrated a high incidence of mental retardation and have resulted in considerable service to the mentally retarded. By participating in multi-service centers, concerted services projects, pilot neighborhood activities and similar efforts, State rehabilitation agencies are extending their services in order to reach and rehabilitate greater numbers of retarded persons living in both rural and urban poverty.

Recent years have seen the development of many new job opportunities for the mentally retarded. Under a jointly sponsored Rehabilitation Services Administration-U.S. Civil Service Commission program for Federal employment of the mentally retarded, for example, State vocational rehabilitation agencies have been certifying retardates as qualified for existing vacancies in Federal installations across the country since the beginning of the program.

B. Vocational Rehabilitation Service Project Grants

Special project grants for the innovation and expansion of vocational rehabilitation services have also been utilized to extend and improve State rehabilitation agency efforts for the mentally retarded. Innovation grants provide the means for State agencies to develop new programs and techniques in order to adapt to changing needs, while expansion grants are designed specifically to increase the number of people rehabilitated by the State agency.

Under the Innovation Program, for example, a project in Idaho has made possible the remodeling of the vocational workshop center at the Idaho State School and Hospital for the Mentally Retarded. A project in Maine, conducted in cooperation with the Manpower Development Program, is preparing mentally retarded persons for suitable placement. In Montana, a rehabilitation facility for both residents and non-residents of the State training school has been supported. In Pennsylvania an evaluation unit program for the visually handicapped mentally retarded has been developed at a State school.

The Expansion Grant Program has supported the growth of sheltered workshop and other facility resources for the mentally retarded in Alaska, Indiana, Louisiana, Massachusetts, Nebraska, Oregon, and Pennsylvania. An expansion project in North Carolina has brought special services to the mentally retarded public offender incarcerated within the prison system; and a project in Washington has enabled a sheltered workshop to expand its operation into a box manufacturing plant.

Within an extensive program of rehabilitation facility improvement, the Rehabilitation Services Administration administers Workshop Improvement grants designed to upgrade the services of sheltered workshops and other facilities by supporting such activities as the employment of additional staff, technical consultation, staff development, and the purchase or rental of equipment.

During fiscal year 1968, 171 Workshop Improvement Grants totaling $3,422,000 were awarded to sheltered workshops, many of which were affiliated with local associations for retarded children. Workshop Improvement Grants were also awarded to residential institutions for the mentally retarded to improve their sheltered workshop programs.

Other rehabilitation facility improvement activities are: (1) a program of technical assistance consultation by means of which contracts may be made with State vocational rehabilitation agencies or with other expert consultants to provide workshops and other facilities with special consultation services; and (2) projects to share in the cost of providing training services for handicapped individuals in public or other nonprofit workshops and rehabilitation facilities. Federal financial participation in the Training Services grant program may assist in the cost of such services as training in occupational skills, work evaluation, work testing, provision of occupational tools and equipment necessary for training purposes and job tryouts.

During fiscal year 1968, Training Services Grants totaling $6,000,000 were awarded to 36 workshops serving the mentally retarded as well as other disabled persons.

C. Social Services within Public Welfare Agencies

The Rehabilitation Services Administration is also responsible for the promotion and maintenance of standards for social services provided by State and local public welfare agencies on behalf of disabled public assistance recipients. Such services are directed toward strengthening individual and family life and helping needy individuals attain the maximum economic and personal independence of which they are capable. Among the disabled clients within the Aid to the Blind and Aid to the Permanently and Totally Disabled Categories are an estimated 115,000 mentally retarded adults.

While there are many special problems and conditions which are of concern to the public assistance programs, mental retardation has particular significance as a frequent cause of economic dependency. Many of these retarded persons cannot live in the community unless special protective services are provided in their behalf. These social services are particularly essential when family members through incapacity or death can no longer provide a protective environment.

Homemaker services, group work services, foster family care, group and volunteer services, and use of additional specialists, such as teachers, psychologists, and counselors, can make special contributions towards meeting the needs of the mentally retarded. Public welfare agencies are responsible for participating with the total community in developing diagnostic treatment, training and employment services, for the mentally retarded, and for developing basic social services to support, encourage, and sustain the mentally retarded in areas of family and social functioning.

The various State public welfare agencies may elect to provide as a minimum the following services: (a) those providing protection for the individual; (b) those which help the client remain in or return to the community; and (c) those services appropriate for self-support. Other services -- to persons with potentials for self-care, to those estranged from family, and to those who are former and potential public assistance applicants and recipients -- may be provided in addition. Special programs providing homemakers, volunteers and groups services may also be furnished in addition to the minimum services. When the States elect to provide these services, Federal matching in the amount of 75 percent is available to meet such costs. About two-thirds of the States have elected to provide at least the minimum services and a further expansion of social service is being encouraged.

D. Mental Retardation Hospital Improvement

The Mental Retardation Hospital Improvement Grant Program is designed to assist State institutions for the mentally retarded to improve their care, treatment, and rehabilitation service. The program is specifically focused on the demonstration of improved methods of service and care, as opposed to research exploration or the development of new knowledge.

Only State residential institutions for the mentally retarded are eligible to apply for these grants. These State institutions are defined as those residential facilities under the administrative direction of State agencies responsible for such institutions. The maximum amount of support, including direct and indirect costs, that an institution can receive under this program for any one budget period (usually 12 months) is one hundred thousand dollars ($100,000). Individual projects are normally approved for no more than a five-year period. Except in unusual instances, individual projects are completed within this approved period. Projects are planned in response to high priority needs in relation to the overall institution plan and are directed toward the ultimate improvement of resident care throughout the institution.

An analysis of the current Hospital Improvement projects shows that a majority of the projects is focused on specialized services for residents who will require long-term care and treatment. A number of these projects involve retardates functioning at the severe and profound levels of retardation; some involve multiply handicapped residents; and a few are concerned with aged residents. Demonstration projects for these more severely retarded and dependent residents are emphasizing personal development by means of self-care training, socialization experiences, intensive medical diagnosis and treatment, and opportunity for improved speech.

A number of projects have focused on special program areas, such as prevocational training for adolescents, and programs of treatment, training, and social habilitation. Other projects provide a diversified range of improved services, such as placement preparation, speech therapy, medical-physical diagnosis and treatment, recreation services, social-vocational habilitation diagnostic study with improved records and program planning and use of the unit system, all of which enhance the development of an institution-community continuum of services.

The Mental Retardation Hospital Improvement project grant program was initiated in 1964 as an extension of the Mental Health project grant program. By the end of 1968, 91 projects in 87 State institutions for the mentally retarded had received awards. There are 169 eligible institutions at this time. This means that approximately 52 percent of the rapidly increasing number of eligible institutions are included in the program. All but five States had at least one grant for an institution for the retarded.

Although the program has been in operation for less than five years, it is already clear that many of the severely and profoundly retarded residents are benefiting. Some are able to participate in more advanced developmental programs of the institution, and others are returning to their families and communities. There is evidence that the success of the patients is changing staff attitudes and "deinstitutionalizing" staff attitudes and behavior. For many institutions the projects are stimulating improved institution-community program coordination, and making possible a more effective use of nearby community, university and college resources.

Major emphasis in this program during the next year will continue to be placed both on the extension of coverage to those institutions not yet involved in the program and on the development of long-term collaborative efforts by the staffs of the institutions receiving grants, their State mental retardation agencies, and the Rehabilitation Services Administration. Such collaboration is being developed so that project experience in solving problems of institutional care of the mentally retarded may be assessed and shared to ensure that improved methods and techniques can be widely disseminated.

The coordination of institutional programs with community service programs and Statewide comprehensive planning activities remains an important objective of the Mental Retardation Hospital Improvement Program.

E. Community Services

Although Community Service projects are administered in the Office of Community Health Service of the Health Services and Mental Health Administration, Public Health Service, the Division of Mental Retardation within the Rehabilitation Services Administration actively stimulates such projects and encourages their submission for competitive evaluation and support.

High priority is given project proposals directed to programs to individuals with moderate to profound intellectual impairment through special health services which could not usually be available through programs presently serving the general population. Grants are available for projects devoted to: (1) new or expanding existing programs to serve the mentally retarded and their families; (2) proposals designed to reflect multiple agency funding when possible; (3) proposals involving the utilization of disadvantaged persons in the program when appropriate; and (4) those involving such activities as community-wide planning, coordination and/or citizen participation as well as the provision of special health-related services such as homemaker services, special therapeutic recreation, or information and referral services.

The first area of priority is being given to projects in target cities,which provide unmet services to the retarded in model cities, ghettos, neighborhood health centers, family planning or coordinated health programs.

II. Recent Legislation

Special provisions in the 1965 Vocational Rehabilitation Amendments (P.L. 89-333) assisted States in meeting the cost of providing vocational rehabilitation services to handicapped individuals in order to determine whether they can reasonably be expected to engage in gainful employment. In the case of the mentally retarded, such services may be extended over a period of 18 months. Previously, State rehabilitation agencies were expected to determine after an initial diagnostic evaluation, but prior to the rendering of any services, whether a handicapped person could reasonably be expected to become employable after his rehabilitation program has been completed. this provision permits State rehabilitation agencies to work with an increased number of more severely retarded clients, and provide them with extended evaluative services in order to determine their real potential for ultimate employment.

Partially as a result of this new opportunity, State rehabilitation agencies are better able to give special attention to developing services for retarded persons with multiple disabilities. Special programs for the mentally retarded blind, for example, are currently being explored in a number of States.

An additional resource for aiding in the rehabilitation of the retarded is the authority in the Social Security Trust Funds for rehabilitation services to selected categories of disability beneficiaries. These supplemental funds will be especially helpful to State vocational rehabilitation agencies in serving the Disabled Children Over Age 18 group, which contains many of the more severely retarded with no past record of employment.

Under the Military Medical Benefits Amendments of 1966 (P.L. 89-614) State rehabilitation agencies are cooperating in the provision of rehabilitation services to moderately or severely mentally retarded dependents of military personnel on active duty.

The 1967 Vocational Rehabilitation Amendments (P.L. 90-99) provided that State plans for vocational rehabilitation must be amended by July 1, 1969, to ensure that no residence requirement will be imposed on eligible clients. This means that any mentally retarded individual present in a State may be evaluated for vocational rehabilitation without regard to how long he may have resided in that State.

These 1967 Amendments also authorized project grants to serve disabled migratory agricultural workers. State rehabilitation agencies and other public or private nonprofit organizations will be able to obtain Federal aid to develop projects which provide rehabilitation services no only to the disabled migratory workers but also to members of his family if such services contribute to the rehabilitation of the worker. Federal funds are expected to be available for this program in fiscal year 1970.

In addition to broadening the scope of rehabilitation services, the 1968 Vocational Rehabilitation Amendments (P.L. 90-391) authorize a new Vocational Evaluation and Work Adjustment Program to serve the disadvantaged, including the physically and mentally handicapped. The Amendments also authorize projects with industry to provide on-the-job training in work settings and eventual employment to handicapped people. Provisions are also made to recruit and train handicapped individuals, including the mentally handicapped, in a wide range of public service employment.

III. Training of Personnel

A. Training Grant Programs

The Rehabilitation Services Administration supports a variety of training grant programs designed to increase both the supply and competence of professional and subprofessional personnel qualified to provide rehabilitative, health and other services to the mentally retarded. Included within the training activity are: (1) grants to educational institutions to employ faculty or otherwise expand or improve their instructional resources (teaching grants); (2) grants to educational institutions for traineeships (stipends) to students; (3) grants to State residential institutions for the mentally retarded and State vocational rehabilitation agencies for in-service staff training; (4) contracts with educational institutions and other agencies to support short-term training programs; and (5) grants to public and private nonprofit agencies and organizations for a program of student work experience and training in mental retardation.

Under the Vocational Rehabilitation Act during fiscal year 1968 there were 39 long-term teaching grants supported at 34 different institutions or organizations, including 31 universities. There were also 6 short-term training grants during this same period. The long-term grants supported the professional education of specialists in social work, speech pathology, and audiology, rehabilitation counseling and physical therapy with 278 traineeships awarded in these areas including 4 traineeships awarded by the Research and Training Center at the University of Oregon. Short-term courses were largely conducted by three RSA-supported centers for short-term training in mental retardation--University of North Carolina, Columbia University and California State College at Los Angeles. These courses reached 743 students during 1968. Two additional courses involved 118 more students. The total amount obligated by RSA in fiscal year 1968 for support of training of rehabilitation personnel in mental retardation was 2,037,191. It is estimated that the 1969 total will be about the same.

Rehabilitation Services Administration activities in fiscal year 1969 in the field of professional preparation include:

--Maintaining level of students in graduate training programs in psychology, social work, rehabilitation counseling, physical therapy, speech pathology and audiology receiving specialized training in the rehabilitation of the mentally retarded through supervised field work in mental retardation settings;

--Improvement in curriculum content and teaching methods in training projects through support of field teachers, the development of case material and other teaching aides, the encouragement of research in the rehabilitation of the mentally retarded, and training courses dealing with the scope, nature and place of content on mental retardation in the curriculum. The teaching films produced by Parsons State Hospital, for example, should be ready for distribution and use by rehabilitation personnel shortly;

--Upgrading of personnel now serving the mentally retarded through short-term training courses of great variety in length, subject matter, intensity, depth and frequency. Included will be professional personnel in all relevant fields, sheltered workshop executives, floor supervisors and others in positions with management responsibilities;

--Encouragement of a comprehensive, interdisciplinary approach to providing care and rehabilitation of the mentally retarded through training courses focused on interdisciplinary program planning and operation of rehabilitation services;

--Stimulation of training programs for assistant or aide positions in such fields as physical therapy, occupational therapy, social work and of educational objectives, curriculum development and preparation of teaching materials;

--Support of training programs for volunteers in rehabilitation of the mentally retarded, not only for assistance to professional personnel engaged in services to individuals or groups, but also for lay leadership in community planning and program development;

--Development of training programs to prepare executives and other management personnel in rehabilitation facility administration, including workshops offering sheltered employment, vocational evaluation or occupational adjustment services;

--Extension and development of training in rehabilitative medicine to include orientation to mental retardation at the undergraduate level and at the residency level in physical medicine and rehabilitation.

Based upon continuation of 1968 projects, 1969 grants made by the RSA will include:

B. Multi-Disciplinary Programs

California State College at Los Angeles;
Columbia University, Teachers College
Devereux Foundation
University of North Carolina

In addition, the SRS-supported Research and Training Centers (Mental Retardation) receive RSA training funds for support of stipends for graduate students. They are the Universities of Oregon, Texas and Wisconsin.

C. Field Instruction Unites

1. Rehabilitation Counseling

California State College at Los Angeles
Columbia University, Teachers College
University of Florida
Michigan State University
New York Medical College
State University of New York at Buffalo
Southern Illinois University
Syracuse University
West Virginia University
University of Wisconsin, Madison

2. Social Work

Boston College
University of California (Berkeley)
University of California (Los Angeles)
University of Connecticut
University of Denver
Louisiana State University
University of Michigan
New York University
Rutgers--The State University

Simmons College
University of Texas
Tulane University
University of Utah
University of Washington
University of Wisconsin (Madison)
University of Wisconsin (Milwaukee)

3. Speech Pathology and Audiology

Michigan State University

4. Physical Therapy

University of Oklahoma

5. Occupational Therapy

Parsons State Hospital

6. Medicine

University of Mississippi
University of Rochester

7. Medical Genetics

University of California

8. Dentistry

Long Island Jewish Hospital
Montana State Board of Health

9. Medical Technology

St. Mary's Junior College
University of Wisconsin

10. Psychology

University of Alabama
Memphis State University
University of Mississippi
University of South Carolina

11. Nursing

California Board of Nursing Education
University of Tennessee

12. Program Management

Florida State University

Short-term training in mental retardation is being conducted by University of Alabama, Boston College, California State College, Columbia University, Denver Board for the Mentally Retarded and Seriously Handicapped, Inc., University of Indiana, National Recreation and Park Association, University of Minnesota, New York Academy of Science, University of North Carolina, University of Southern California, University of Wisconsin.

The long-term multidisciplinary training programs at the University of Wisconsin, the University of Oregon and the University of Texas are now operating within Social and Rehabilitation Service Research and Training Centers. Long-term traineeships at these Centers are supported by Rehabilitation Services Administration funds and 14 such traineeships were awarded by the Research and Training Centers in fiscal year 1968. Although the underlying content and intent of the multidisciplinary courses supported under the Vocational Rehabilitation Act are geared to vocational rehabilitation, the programs will serve many other professional disciplines either in their own professional grouping or in courses serving several professional disciplines.

Individual traineeship grants have also been awarded to 65 post-resident, graduate, and post-graduate nursing students to pursue professional careers in mental retardation in such fields as medicine, dentistry, psychology, social work, nursing, recreational therapy, speech therapy, and music therapy.

D. Hospital Inservice Training

The Rehabilitation Services Administration is especially concerned with improving the quality of service within institutions for the mentally retarded. Hospital Inservice Training grants have been designed to provide a continuing means for increasing the effectiveness of employees in State training schools and other state residential institutions for the mentally retarded.

One hundred and nine of the eligible State residential facilities in 46 States and 2 territories are receiving a total of $2,182,000 through the Hospital Inservice Training program and are translating the rapidly expanding body of knowledge about practices in the care of the mentally retarded into more effective services.

Hospital inservice training has been broadly defined to include: pre-service training, job-related training, inservice training, continuing education, special training and technical training needed to introduce new methods, and training of personnel which will result in an improved quality of care for the mentally retarded residing in institutions.

Because personnel such as attendants, houseparents, psychiatric aides, and others in similar personnel categories comprise the major portion of those rendering direct care to institutionalized retardates, the first major area of grant support was extended to these personnel. Grant support is available for inservice training of all professional, subprofessional, and technical personnel who have direct responsibilities for resident care and training.

Every State residential facility for the mentally retarded is eligible to participate in this program. The maximum grant to a single institution may not exceed $25,000 in any one year. These grants can be made for a period of up to seven years and are renewable.

There are four general types of training supported by inservice training grants to institutions for the mentally retarded: (a) orientation and initial on-the-job training for employees; (b) refresher, continuation, and other special job-related training courses; (c) continuation training for technical and professional staff to keep them informed of new developments in their fields which can be translated into more effective patient service; and (d) special instructor training for staff with inservice training responsibilities aimed at providing a cadre of personnel to continue and extend the institutional training program.

The personnel categories involved as trainees in these programs have been, in order of descending frequency, aides, attendants, charge aides, supervisors, registered nurses, and practical nurses.

The content of the training programs includes general instruction in the areas of mental retardation; child growth and development; nursing care skills; patient-staff relations; human behavior; intra-staff relations; supervisory skills; communications skills; and adjunctive therapy skills.

Consultation is given to the institutions which have received grants to assist them in making the best use of training opportunities. Technical information and professional consultation is being provided to the remaining State institutions for the mentally retarded in order to enable them to qualify for similar grants.

E. Student Work Experience and Training

A program of Student Work Experience and Training (SWEAT) projects provides students with both employment and training during summer months and other vacation periods, while working directly with mentally retarded children and adults.

The program is open to high school seniors, college, and graduate students and generally offers to these young people experience in all phases of work with the mentally retarded.

Twenty-eight projects, in which approximately 298 students are participating, are being supported. It is hoped that, as a result of this experience, many of these students will be attracted to careers in mental retardation.

IV. Construction

A. Community Facilities for the Mentally Retarded

The community facilities construction program authorized under Title I, Part C of the "Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963" (P.L. 88-164) provides Federal grants to States to assist in the construction of specially designed public or other nonprofit facilities for the diagnosis, treatment, education, training, or custodial care of the mentally retarded, including sheltered workshops which are part of a facility providing comprehensive services. The program is administered at the State level by an officially designated State agency. Participation in the program requires the development of a State plan for the construction of community facilities for the mentally retarded based on an inventory of needed additional services and facilities. Construction projects are approved in accordance with the provisions of the State plan.

All States are participating in the program. As of December 1968, 241 projects have been approved. Fifty-three facilities are completed and in operation, and 100 additional facilities are under construction. These facilities will provide care and treatment for approximately 27,000 additional retarded persons not now being served. The estimated total cost of these projects is over $148 million with an estimated Federal share of over $48 million.

The program is having a widespread impact on community efforts to meet the needs of the retarded. Public and voluntary agencies are demonstrating increased interest in participating in the construction program, and community leaders and professional personnel are combining efforts to stimulate sponsorship of needed facilities. Accomplishments to date, however, have only slightly touched on the need for additional services and facilities. State plans indicate that services should be provided for about one million additional retarded individuals.

B. Construction of Rehabilitation Facilities

The Vocational Rehabilitation Amendments of 1965 (P.L. 89-333) authorized a program for the construction of rehabilitation facilities and workshops; the construction of rehabilitation facilities and sheltered workshops; and initial staffing support for newly constructed rehabilitation facilities and workshops. Special provisions are made to permit the inclusion of residential facilities within projects for the construction of workshops for the mentally retarded.

State Planning grants for workshops and rehabilitation facilities encompass: (1) the development of State Workshop and Rehabilitation Facilities Plan; and (2) construction, utilization, development, and improvement of workshops and rehabilitation facilities.

Project Development grants pay part of the cost of organized, identifiable activities necessary for the planning and development of specific local construction projects for rehabilitation facilities or workshops. These projects are oriented particularly towards assisting local citizens groups with limited financial resources to engage consultants and secure other types of help to develop a sound project proposal.

During fiscal year 1968, 38 Project Development Grants, having a national average of $7,000, were made to applicants planning a specific construction project providing services to the mentally retarded.

Construction grants assist in the costs of the new construction of rehabilitation facilities and workshops; the acquisition, expansion and alteration of existing facility and workshop buildings; initial equipment for the completed projects.

Twenty-seven construction grants totaling about $3,000,000 were awarded during fiscal year 1968. These projects were for the construction of workshops, and comprehensive rehabilitation centers, and one was for the construction of a comprehensive speech and hearing rehabilitation center. Most of these projects are multidisability in nature and serve the mentally retarded as well as other disability groups. Workshops serving the retarded were constructed in Lebanon, Pennsylvania, and Casper, Wyoming.

C. University-Affiliated Facilities for the Mentally Retarded

The University-Affiliated Facilities for the Mentally Retarded program assists universities or affiliated facilities for the mentally retarded in the construction of special clinical facilities capable of demonstrating exemplary care, treatment, education and habilitation of the mentally retarded. In University-Affiliated Clinical facilities comprehensive services are provided; specialized personnel are trained; or new techniques of specialized service are demonstrated.

The primary purpose of this program is to provide facilities for the clinical training of physicians and other professional and technical personnel in the field of mental retardation. Among the professional disciplines represented in these facilities are medical personnel, dentists, nurses, speech and hearing therapists, nutritionists, physical therapists, occupational therapists, rehabilitation specialists, special educators, psychologists, social workers, recreational specialists and chaplains. Each facility is encouraged to conduct a comprehensive multidisciplinary training program so that each discipline involved in the care and rehabilitation of the mentally retarded may be fully familiar with the contributions of the other disciplines.

The Mental Retardation Amendments of 1967 (P.L. 90-170) extended the university-affiliated construction program until June 1970. The present law was also amended to provide grants for the construction of university-affiliated facilities which include programs for persons with other neurological handicapping conditions related to mental retardation and for research incidental or related to activities conducted within the facility.

Because of the complexity of the university-affiliated program, individual planning grants are available. Such individual grants may not exceed $25,000 nor more than 75 percent of the planning costs.

Examples of approved projects for the construction of university-affiliated facilities for the mentally retarded are: Children's Rehabilitation Institute, Reisterstown, Maryland; University of Colorado, Denver, Colorado; Walter E. Fernald State School, Waltham, Massachusetts; Children's Hospital Medical Center, Boston, Massachusetts; Georgetown University, Washington, D.C.; University of California Neuropsychiatric Institute, Los Angeles, California; University of Alabama Medical Center, Birmingham and Tuscaloosa, Alabama; Indiana University Medical Center, Indianapolis and Bloomington, Indiana; University of N.C., Chapter Hill, North Carolina; University of Tennessee, Memphis, Tennessee; New York Medical College, New York, New York; Georgia Department of Public Health, Atlanta, and Athens, Georgia; University of Oregon, Portland, Oregon, and Eugene, Oregon; University of Miami, Miami, Florida; and Utah State University, Logan, Utah.

V. Initial Staffing of Community Facilities for the Mentally Retarded

The Mental Retardation Amendments of 1967 (P.L. 90-170) added a new program to stimulate and aid local communities in responding to the unmet needs of the retarded by providing grants to pay for the initial cost of professional and technical personnel in the operation of new facilities or for new services in existing facilities for the mentally retarded. Over eight million dollars was appropriated in 1969 fiscal year to implement the program.

Funds are approved for individual projects sponsored by local nonprofit community organizations or public agencies on a declining basis for 51 months. During the first 15 months, the grant may not exceed 75 percent of the cost; 60 percent for the next year; 45 percent for the third year; and 30 percent for the last 12 months.

The program is authorized for continuation through June 30, 1970, and an additional $14 million is authorized to be appropriated for new projects.

VI. Planning

A. Mental Retardation Planning and Coordination

State planning for comprehensive coordinated services to the mentally retarded was begun in 1964 under P.L. 88-156 and is now supported under P.L. 89-97 in the form of continued planning, the development of mechanisms for the coordination of programs of State agencies dealing with the mentally retarded, and the mobilization of community support.

Although the implementation programs vary greatly from State to State, progress is evident in all areas. For example, stress has been placed on community planning in Colorado, North Carolina, Florida, and Nebraska. The division of a State into regions for better assessment and projection of programming is being emphasized in Illinois, Indiana, Connecticut, and Wisconsin. Special projects with primary attention to implementation objectives have been undertaken in Texas, New York, Michigan, and Montana.

Funding of new projects terminated in the spring of 1968; however, some projects were extended through December 1968. Indications are that in a majority of the States these planning and implementation activities are continuing and will continue under State sponsorship on a permanent basis, thus providing conformity and assuring coordinated services to the mentally retarded. Consultation from the Federal level will also continue, including analysis of data coming out of the planning and implementation projects.

B. Vocational Rehabilitation Planning

The Vocational Rehabilitation Amendments of 1965 authorized a program of grants to States to plan for the orderly development of comprehensive vocational rehabilitation services, including services provided by private, nonprofit agencies. These plans, which will involve careful consideration of the rehabilitation needs of the mentally retarded have the objectives of making vocational rehabilitation services available by 1975 to all handicapped individuals who need them. Fifty-two comprehensive Statewide planning projects are now being undertaken by State vocational rehabilitation agencies and other designated agencies throughout the country. Upon completion of this special grant program, States will be conducting continuing Statewide studies of the needs of the handicapped and how these needs may be most effectively met.

State Planning Grants for Workshops and Rehabilitation Facilities provide for the coordinated and orderly development of the total State-Federal facilities effort. Initial State Workshops and Rehabilitation Facility Plans have been completed in the 49 States receiving grants. These States received continuation grants for a second year during which the plans are being updated and refined. Upon completion of the continuation grants in June 1968, this program will become a part of the State vocational rehabilitation agency operation, thus assuring a permanent program in each State agency for assessing needs and evaluating activities for establishment, construction, utilization, development, and improvement of workshops and rehabilitation facilities.

VII. Information

A. Collection and Dissemination of Information

Since September 1968, the special mental retardation review, abstracting and information activity has been operated as part of the Social and Rehabilitation Service. In previous years this service was a part of the National Clearinghouse for Mental Health Information. Because knowledge about mental retardation comes from many scientific disciplines and professions, this service will improve both research and practice and thus have a decided effect on the prevention and treatment of mental retardation.

To maintain this service, the Social and Rehabilitation Service under contract with the American Association on Mental Deficiency, collects current literature on mental retardation, writes informative abstracts, indexes the literature in depth, compiles annotated bibliographies on special topics, and prepares critical reviews. In 1964, a total of 9,300 current articles, books and monographs have been collected, abstracted, and indexed. To provide a more extensive coverage of information for retrieval purposes, an additional 3,500 indexed abstracts of documents published from 1957 through 1963 were added to this system.

Special annotated bibliographies have been prepared on: (1) Programmed Instruction with the Retarded; (2) Literature for Parents; (3) Application on the Stanford-Binet and Wechsler Intelligence Scales with the Mentally Retarded; (4) Nursing and Mental Retardation; (5) Family Care and Adoption of Retarded Children; (6) Psychotherapy with the Mentally Retarded; (7) Recreation for the Retarded; (8) Counseling Parents of the Mentally Retarded; (9) Sheltered Workshops for the Mentally Retarded; (10)Films on Mental Retardation;

(11) Psychopharmacological Therapy with the Mentally Retarded; (12) Electroencephalographic Studies Relating to Mental Retardation; (13) Hydrocephalus; (14) Mental Retardation and Religion; (15) A Selected List of Teaching Materials Regarding Mental Retardation for Faculty of Schools of Social Work; (16) Architectural Planning for the Mentally Retarded to Remove Barriers and Facilitate Programming; (17) Inservice Training in Institutions for the Mentally Retarded.

Review articles and critiques have been prepared on: (1) Mental Retardation: Definition, Classification, and Prevalence; (2) Research on Linquistic Problems of the Mentally Retarded; (3) Attendant Personnel: Their Selection, Training, and Role; (4) Research on Personality Disorders and Characteristics of the Mentally Retarded; (5) Effects of Severely Mentally Retarded Children on Family Relationships; (6) Factor Analysis and Structure of Intellect applied to Mental Retardation; (7) Counseling Parents of the Mentally Retarded; (8) Genetic Aspects of Mental Retardation; (9) Instrumental Learning in Mental Retardates; (10) Vocational Rehabilitation of the Mentally Retarded: The Sheltered Workshop; (11) Relationships between Educational Programs for the Mentally Retarded and the Culturally Deprived; (12) A Decade of Research on the Education of the Mentally Retarded; (13) Application of Operant Conditioning Techniques to Institutionalized Severely and Profoundly Retarded Children; (14) Adaptive Behavior: A New Dimension in the Classification of the Mentally Retarded.

The abstracts, annotated bibliographies, and reviews appear in the quarterly journal Mental Retardation Abstracts, which is distributed gratis to approximately 6,000 individuals engaged in research and practice in mental retardation and is also for sale by the Superintendent of Documents.

B. Films and Publications

The Rehabilitation Services Administration continues to distribute a documentary film, "Handle with Care," stressing the value of a fixed community point of referral upon which the families of the mentally retarded can depend for continuing lifetime guidance and assistance in obtaining appropriate services. The film has been placed in State health departments and medical school film libraries for wider distribution.

A second film, "Teaching the Mentally Retarded--A Positive Approach," a documentary dealing with behavior shaping, was placed in circulation during 1967. It is aimed at child-care workers and attendants as well as students who are preparing to work with the mentally retarded.

A third film was produced in 1968. This film "A Way Out of the Wilderness" depicts care, treatment, and training activities in a private institution and a large State institution for the mentally retarded. The film was developed to sharpen the awareness of the general public to today's problems and promises in institutional care for the retarded.

A package of training materials for parents of retarded children and personnel in residential and day facilities for the retarded provides information on training mentally retarded children in feeding skills and toilet use. The materials which include filmstrips, records, a discussion guide and pamphlets provide helpful directions for both individual and group training in these two basic skills which are a major step toward self-care and increased independence.

The packages of training materials "Growing Up at the Table" (individual and group) and "Diapers Away" (individual and group) are available on a free short term loan basis from:

National Medical Audiovisual Center (Annex)
Chamblee, Georgia 30005

Numerous publications have been prepared and placed in circulation. One in particular, "A Modern Plan for Modern Services," states the basic philosophy of the Division of Mental Retardation in 6 major points. Briefly stated, these points emphasize: (1) utilization of generic community agencies in lieu of establishing specialized services; (2) provision of basic training in mental retardation for every category of service personnel; (3) definition for utilization of specialized services and agencies; (4) placement of a mental retardation specialist in every generic agency; (5) development of standards for service and training; and (6) coordination within the community.

Two other publications are worthy of note: (1) Opportunity: Help for the Mentally Retarded, provides a brief description of rehabilitation services available to the retarded, eligibility requirements and a list of the State rehabilitation agencies where further information may be acquired; (2) A Mental Retardation Film List, sponsored by the Division of Mental Retardation provides a list of films of interest to both professional and to the general public. Brief descriptions of each film and the sources from which each may be borrowed, rented and/or purchased are included in the pamphlet.

SOCIAL SECURITY ADMINISTRATION

The social security program today is the basic method in the United States of assuring income to individuals and families who suffer a loss of earnings when workers retire, become disabled, or die and, since July 1, 1966, health insurance protection to persons 65 and over.

Economic Impact

Under social security's "Childhood Disability" provisions, lifetime monthly payments can be made to a person age 18 or over who has been disabled by mental retardation--or other impairments--since childhood. In many cases, the monthly benefits enable the retarded childhood disability beneficiary to be cared for at home instead of in an institution. Furthermore, as more and more retarded people outlive their parents, the program offers reassurance to fathers and mothers who know that financial help for their disabled child will be forthcoming even after their death. (About half of the childhood disability beneficiaries are over 35 and 25 percent of them are over 45.)

The problem of mental deficiency is a major factor in more than 65 percent of the beneficiary groups having disabilities which began in childhood. It is the primary diagnosis in about half of this group. In fiscal year 1968 an estimated 153,000 adult mentally retarded beneficiaries received $107,900,000 in social security benefits. The number of mentally retarded children under age 18 who receive payments as dependents of retired, disabled, or deceased workers is unknown, since their benefits are payable regardless of disability.

If the parents are dead, a relative who has demonstrated a continuing interest in the beneficiary's welfare, a welfare agency, or a legal guardian may be chosen as representative payee to handle the benefit funds and plan for using them in behalf of the beneficiary. A representative payee receives social security benefits in trust for the beneficiary and, as a trustee, is held accountable for the way in which he uses the benefits.

Health insurance benefits under the social security law are available to any individual, including a mentally retarded individual who is 65 or over and who meets certain necessary conditions. Therefore, a mentally retarded individual 65 years of age who has contracted an illness or suffered an injury is, like any other person in this age group, protected under the health insurance program. However, the health insurance for the aged program specifically prohibits reimbursement under the law for expenses incurred for personal care designed primarily to aid an individual in meeting the activities of daily living and which do not require the continuing attention of trained medical or paramedical personnel. Therefore, an aged mentally retarded person whose only deficiency is mental retardation requiring general institutional care, e.g., vocational training, help in the activities of daily living, and so forth would not be receiving the type of care covered under the Medicare program.

Activities and Achievements

All district offices of the Social Security Administration maintain a referral service to other programs and services of both public and private agencies and organizations. Giving information about these programs and agencies is an essential part of the Social Security Administration's service to the public. The service is provided to beneficiaries as well as to non-beneficiaries and applicants who inquire about services not provided by the OASDHI program. Disabled persons applying for disability benefits under social security are promptly referred to the Rehabilitation Services Administration to the end that the maximum number may be rehabilitated into productive activity or to a level of self-care. The information and referral service is currently under study to determine what changes are indicated to make the program more responsive to the needs of people and the multiplicity of problems they bring to district offices.

SSA has participated in the employment of the mentally retarded since the inception of the employment program in 1964. Experience has demonstrated conclusively that the retardate can perform excellent work in basically routine positions when placement is carefully selected or the job re-engineered to the level or degree of his handicap. In SSA, retardates are successfully performing in such positions as mail and file clerk, messenger, printing machine operator, and xerox machine operator.

After success on a pilot project, placements have been greatly increased in the last year at SSA headquarters and payment centers by utilizing retardates in the operation of card reader machines which control the location of claims folders. Retardates are performing in a highly successful manner and many have been promoted to a grade GS-2. One has performed so well in the Division of Personnel at headquarters, that the Maryland State Division of Vocational Rehabilitation has certified her capable for promotion to a grade GS-3 position.

A significant development at the Baltimore headquarters complex was the establishment of a training seminar, in cooperation with specialists from the Maryland State Division of Vocational Rehabilitation, for supervisors of retardate program employees.

As of September 30, 1968, a total of 126 retardates were on duty as follows: 32 in central headquarters offices, 48 in payment centers, and 46 in district offices.

In the area of public information, a number of steps were taken during fiscal year 1968 to publicize the childhood disability provisions of the social security program. All the materials produced emphasized early filing and the high incidence of mental retardation among childhood disability beneficiaries. Major activities included:

1. Articles were carried by many national medical and health publications, including KNOW Your World (Teacher's Edition, read by special education teachers), Medical World News, Physician's Management, Rehabilitation Literature, American Association of Industrial Nurses Journal, Resident Physician, and The New Physician.

2. The American Academy of Pediatrics distributed a leaflet, "Special Social Security Benefits for Persons Disabled in Childhood," to its 8000 members. The leaflet urges physicians to refer patients who may be eligible for benefits to social security.

3. A release was sent to the National Association for Retarded Children for distribution to its 1150 State and local components. Following this, in November 1967, a member of BDI's top staff addressed the annual convention of the NARC.

An exhibit, "Childhood Disability and Social Security," had its premier showing at the convention of the American Orthopsychiatric Association in Washington, D.C., in March 1967. Since then it has been shown at numerous meetings of national organizations and medical groups interested in the handicapped. In the very near future it will be revised to update statistics on the number of mentally retarded childhood disability beneficiaries and the percentage of childhood disability beneficiaries for whom mental retardation is the primary diagnosis.

A 20-minute film on mental retardation, "Where There Is Hope," will be released by the Social Security Administration about February 1969 in both 35mm and 16mm color for theatrical and general showing. Early sequences in the film deal with diagnosis and therapy at the John F. Kennedy Institute in Baltimore.

These are followed by scenes filmed at a sheltered workshop in Washington, D.C., showing the activity of teenagers and older people, and finally scenes showing rehabilitation services for a 21-year old girl just completing a trial work period in Greensboro, North Carolina. The film tells of the social security benefits available for the adult disabled child. A 14½-minute version is now in use as part of the "Social Security in America" series being shown in 184 television stations throughout the country.

The Social Security Administration has developed a pamphlet entitled, "Social Security: What It Means For The Parents Of A Mentally Retarded Child." This pamphlet describes the conditions under which a mentally retarded child may be eligible for social security benefits. It is available in both English and Spanish. The present edition includes information about the 1967 amendments. About a half million of these pamphlets have been distributed in recent months.

The Social Security Administration conducted a nationwide survey in the fall of 1967 which will supply basic information about institutionalized adults, including the mentally retarded in institutional care. The 1967 surveys of institutionalized adults examined the socio-economic characteristics of mentally retarded persons (as well as other disabled persons) over age 18 in institutions such as homes and schools for the mentally or physically handicapped, mental hospitals, chronic diseases and other long-term hospitals. This survey focused on the types of care they received, the cost of care, and sources of payment, the economic resources of the patient and his family, and his family relationships.

The 1966 survey of disabled adults (non-institutionalized) will also provide a wide range of data on financial, medical, and family arrangements of disabled adults who are mentally retarded.

Obligations for Mental Retardation Programs by Agency Designation
Fiscal Years 1968-1970
(In Thousands of Dollars)

Social Security Administration	1968	1969	1970
Estimated benefits from the trust funds...	107,900	131,300	141,700
Trust fund obligations incurred to adjudicate claims from beneficiaries....	1,900	2,400	2,600
Total-Social Security Administration	109,800	133,700	144,300

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

Obligations for Mental Retardation Programs
by Agency Designation
Fiscal Years 1966-1970
(Thousands of Dollars)

AGENCY	1966	1967	1968	1969 Estimated	1970 Estimated
Health Services and Mental Health Administration					
Comprehensive Health Planning and Services	$ -0-	$ 5,485	$ 4,071	$ 3,475	$ -0-
Mental Health Research and Services	11,636	8,279	1,556	1,627	1,495
National Health Statistics	19	21	21	6	-0-
Total, Health Services and Mental Health Administration	11,655	13,785	5,648	5,108	1,495
National Institutes of Health					
Neurology and Stroke Activities	22,028	19,473	21,384	21,950	21,600
Child Health and Human Development	8,500	12,134	13,680	15,608	16,486
Grants for Construction of Health Research Facilities	6,234	6,026	-0-	-0-	-0-
Total, National Institutes of Health	36,762	37,633	35,064	37,558	38,086
Office of Education					
Elementary and Secondary Education Activities	20,963	27,512	30,589	37,218	40,438
Educational Improvement for the Handicapped	8,977	10,024	17,410	27,200	29,600
Education Professions Development	-0-	-0-	-0-	129	150
Libraries and Community Services	-0-	-0-	-0-	90	90
Research and Training	255	165	38	25	20
Vocational Education	-0-	-0-	-0-	-0-	11,500
Total, Office of Education	30,195	37,701	48,037	64,662	81,798

AGENCY	1966	1967	1968	1969 Estimated	1970 Estimated
Social and Rehabilitation Service					
Vocational Rehabilitation					
Grants to States	$13,764	$22,855	$27,800	$40,860	$61,760
Research and Demonstration Activities	3,713	3,764	2,867	2,909	3,035
Innovation and Expansion Grants	311	475	570	574	574
Facility Improvement Grants	283	1,302	3,400	3,700	3,900
Training and Traineeships	1,501	1,700	1,760	1,760	1,760
Rehabilitation Facilities and Construction Grants	325	1,000	866	828	472
Mental Retardation					
Staffing Grants	-0-	-0-	-0-	8,358	12,000
Hospital Improvement	8,909	8,790	8,610	8,972	8,972
Rehabilitation Service Projects	-0-	-0-	-0-	-0-	4,500
Research	36	32	126	126	126
Construction	20,562	32,339	16,680	27,113	13,531
Planning	2,120	1,523	1,394	-0-	-0-
Maternal and Child Health and Welfare					
Grants to States	11,220	11,843	12,740	12,990	12,990
Training and Traineeships	5,865	9,865	12,865	14,865	17,065
Research and Demonstration	2,759	2,957	3,300	3,300	3,200
Medical Assistance - Grants to States 1/	13,100	28,500	30,000	75,000	100,000
Public Assistance - Grants to States 2/	37,900	51,000	55,000	65,000	75,000
Total, Social and Rehabilitation Service	122,368	177,945	177.978	266,355	318,885
Social Security Administration					
Estimated Benefit Payments from Trust Funds	84,500	93,600	107,900	131,300	141,700
Trust Fund Obligations Incurred to Adjudicate Claims of Beneficiaries	1,800	1,600	1,900	2,400	2,600
Total, Social Security Administration	86,300	95,200	109,800	133,700	144,300

AGENCY	1966	1967	1968	1969 Estimated	1970 Estimated
Office of the Secretary					
Secretary's Committee on Mental Retardation 3/	$(238)	$ (105)	$ (128)	$ (160)	$ (160)
President's Committee on Mental Retardation 4/	-0-	(316)	577	580	605
Total, Office of Secretary	--	--	577	580	605
Total, Services and Grants	163,080	216,064	212,304	309,263	365,869
Total, Income Maintenance	124,200	146,200	164,800	198,700	219,300
GRAND TOTAL, ALL FUNDS	287,280	362,264	377,104	507,963	585,169

1/ These expenditures are based on present experience with six States claiming an average of approximately $5 million per State for a full year for the care of the retarded in State institutions. Fifteen States for 1969 and twenty States for 1970 are estimated in the amounts shown. There is presently no method available for estimating title XIX payments for the care of the retarded outside of State institutions.

2/ Exact information is not available on the costs due to mentally retarded people who are receiving public assistance because data secured does not single out this one cause as a factor of disability or dependency. However, it is known that mental retardation is an important cause of disability for those receiving aid to the permanently and totally disabled under the Federal-State public assistance program. The amounts shown here are estimates based on a constant percentage of total payments under this part of the program.

3/ Shown as non-add items since they were derived from funds available to other agencies for mental retardation activities.

4/ Beginning in 1968 this item is included in direct funding as a line item.

Mr. **Black**. The Department has responded to the needs of the retarded through a broad range of approaches which include preventive services, training of personnel, facility construction, research, education, and other supportive services.

The estimated budget requested for 1970 includes $585,169,000 for mentally retarded persons and for prevention of mental retardation with the following breakdown:

Services, research, education, and rehabilitation	$365, 869, 000
Income maintenance:	
SRS	75, 000, 000
SSA	144, 300, 000
Total, income maintenance	219, 300, 000
Total	585, 169, 000

This estimated total of $585 million for 1970 is more than $77 million above the comparable figure for 1969. And the bulk of that increase—approximately $56 million—is for services and grants.

I would like to give you just a very brief idea of what types of activities are covered.

Senator **Kennedy**. May I ask for some further information here? In your testimony, you state that the estimated budget request for 1970 includes $585 million for mentally retarded persons and for prevention of mental retardation, followed by a breakdown into two categories. Do the figures you break down there include other services to other individuals who have other afflictions?

You do not want to represent that that $585 million is just for the mentally retarded, do you?

Mr. **Black**. Yes, Senator, we do. Particularly on services, research, education, rehabilitation, the figures that we will present for the record here in this report are broken down to try to show the expenditures for the retarded alone. These are parts of larger programs. But in all cases I believe it is accurate to say that the figures which we are using represent the best judgment that our people can make on the amount of these funds that are going specifically to the retarded.

Senator **Kennedy**. I would like to get some additional breakdown of those figures.

Mr. **Black**. There is a more complete breakdown, Senator, in the complete report.

Senator **Kennedy**. On the item of $585 million?

Mr. **Black**. Yes, sir. It shows how these funds are spent by the various agencies in our Department. The report, itself, as you can see here, is a very voluminous report, which takes up our effort agency by agency, and shows what is being done in the area of research, training, direct services and others.

We do, as I indicated, want to put the complete report in the record. If there are questions after you have had an opportunity to study it, we will be glad to provide details on that.

Senator **Kennedy**. All right. It will be made part of the record.

(The information follows:)

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

Obligations for Mental Retardation Programs, by Activity Designation, Fiscal Years 1969–70

HEALTH SERVICES AND MENTAL HEALTH ADMINISTRATION

[In thousands of dollars]

Activity	1969 estimated	1970 (estimated)		1970 budget decrease
		January budget	Revised budget	
Services to or for the mentally retarded: Comprehensive health planning and services	1,738	0	0	
Training:				
Mental health research and services	551	870	842	—28
Comprehensive health planning and services	1,737	0	0	
Total, training	2,688	870	842	—28
Research:				
Mental health research and services	600	600	600	
St. Elizabeths Hospital	24	25	25	
National health statistics	6	0	0	
Total, research	630	625	625	
Other: Mental health research and services (abstracts)	52	0	0	
Total, Health Services and Mental Health Administration	5,108	1,495	1,467	—28

SOCIAL SECURITY ADMINISTRATION

Activity	1969 estimated	1970 January budget	1970 Revised budget	1970 budget decrease
Income maintenance:				
Estimated benefit payments from trust funds	131,300	141,700	141,700	
Trust fund obligations incurred to adjudicate claims of beneficiaries	2,40[illegible]	2,600	2,600	
Total, Social Security Administration	133,7[illegible]	144,300	144,300	None

NATIONAL INSTITUTES OF HEALTH

Activity	1969 estimated	1970 January budget	1970 Revised budget	1970 budget decrease
Training:				
Neurology and stroke activities	10,000	9,630	[1] 9,000	−630
Child health and human development	3,066	2,819	2,754	−65
Total, training	13,066	12,449	11,754	−695
Research:				
Neurology and stoke activities	11,950	11,970	11,153	−817
Child health and human development	12,542	13,667	12,646	−1,021
Total, research	24,492	25,637	23,799	−1,838
Construction: Grants for health research facilities	0	0	0	
Total, National Institutes of Health	37,558	38,086	35,553	−2,533

SOCIAL AND REHABILITATION SERVICE

Activity	1969 estimated	1970 (estimated) January budget	1970 (estimated) Revised budget	1970 budget decrease
Services to or for the mentally retarded:				
Vocational rehabilitation:				
Grants to States	40,860	61,760	55,584	—6,176
Innovation grants	124	124	124	
Expansion grants	450	450	450	
Facility improvement grants	3,700	3,900	3,900	
Total, vocational rehabilitation	45,134	66,234	60,058	—6,176
Mental retardation:				
Staffing grants:				
New grants	8,358	4,895	4,895	
Continuations	0	7,105	7,105	
Hospital improvement grants	6,790	6,790	6,790	
Rehabilitation service projects (VR act, sec. 4)	0	2,000	2,000	
Total, mental retardation	15,148	20,790	20,790	
Medical assistance (title XIX) [2]	75,000	100,000	90,000	—10,000
Maternal and child health and welfare:				
Maternal and child health services	6,988	6,988	6,988	
Crippled children's services	6,002	6,002	6,002	
Total, maternal and child health welfare	12,990	12,990	12,900	
Total, services to or for the mentally retarded	148,272	200,014	183,838	—16,176
Training of professional and supportive personnel:				
Vocational Rehabilitation	1,760	9,760	1,500	—260
Maternal and child health and welfare:				
Training for health and related care of mothers and children (sec. 511, formerly sec. 516)	9,000	11,200	9,000	—2,200
Child welfare training	100	100	100	
Maternal and child health services	2,767	2,767	2,767	
Crippled children's services	2,998	2,998	2,998	
Total, maternal and child health and welfare	14,865	17,065	14,865	—2,200
Mental Retardation:				
Hospital inservice training grants	2,182	2,182	2,182	
Rehabilitation services projects (VR act, sec. 4)	0	2,500	2,500	
Total, mental retardation	2,182	4,682	4,682	
Total, training	18,807	23,507	21,047	—2,460
Research:				
Vocational rehabilitation:				
Research and demonstration projects	1,359	1,385	1,385	
Special rehabilitation research and training centers	950	950	950	
Research and training (special foreign currency program)	600	700	500	—200
Total, vocational rehabilitation	2,909	3,035	2,835	—200
Maternal and child health and welfare:				
Research in maternal and child health services and crippled children's services	2,000	2,000	2,000	
Child welfare research and demonstration	1,300	1,200	1,200	
Maternal and child health and welfare	0	0	0	
Crippled children's services	0	0	0	
Total, maternal and child health and welfare	3,300	3,200	3,200	
Mental retardation: Health services activities (PHS Act)	126	126	126	
Total, research	6,335	6,361	6,161	—200
Construction:				
Mental retardation:				
University-affiliated facilities	9,100	0	0	
Community facilities	18,013	13,531	13,531	
Total, mental retardation	27,113	13,531	13,531	
Rehabilitation facilities and construction grants	828	472	100	—372
Total construction	27,941	14,003	13,631	—372
Income maintenance: Public assistance: [3] Grants to States	65,000	75,000	75,000	
Total, Social and Rehabilitation Service	266,355	318,885	299,677	—19,208

OFFICE OF EDUCATION

Activity	1969 estimated	1970 (estimated) January budget	1970 (estimated) Revised budget	1970 budget decrease
Services to or for the mentally retarded:				
Elementary and secondary education activities (ESEA):				
Title I	32,000	35,000	35,000	
Title III	5,218	5,438	3,647	−1,791
Title VI[4]	15,555	16,000	16,000	
Vocational education activities, Vocational Education Act (pt. B)	0	11,500	11,500	
Early education of the handicapped	445	1,500	1,500	
Total, services to or for the mentally retarded	53,218	69,438	67,647	−1,791
Training:				
Educational improvement for the handicapped	10,000	10,000	10,000	
Educational professions development	129	150	150	
Total, training	10,129	10,150	10,150	
Research:				
Cooperative Research Act, Public Law 85-531 (as amended)	25	20	20	
National Defense Education Act (title VII)	0	0	0	
Vocational education activities, Public Law 88-120	0	0	0	
Educational improvement for the handicapped	1,200	2,100	2,100	
Total, research	1,225	2,120	2,120	
Other:				
Libraries Services and Construction Act (title IV)	15	15	15	
University Community Services Public Law 89-329 (title I)	75	75	75	
Total, other	90	90	90	
Total, Office of Education	64,662	81,798	80,007	−1,791

Total funds including both services and income maintenance	$561,004
Total decrease services and grants	−23,560
Total decrease income maintenance	None
Total decrease all funds	−23,560

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[1] Includes both mental retardation grants in other programs relevant to mental retardation.

[2] These expenditures are based on present experience with 6 States claiming an average of approximately $5,000,000 per State for a full year for the care of the retarded in State institutions. 15 States for 1969 and 20 States for 1970 are estimated in the amounts shown. There is presently no method available for estimating title XIX payments for the care of the retarded outside of State institutions.

[3] Exact information is not available on the costs due to mentally retarded people who are receiving public assistance because data secured does not single out this one cause as a factor of disability or dependency. However, it is known that mental retardation is an important cause of disability for those receiving aid to the permanently and totally disabled under the Federal-State public assistance program. The amounts shown here are estimates based on constant percentage of total payments under this part of the program.

[4] Includes 50 percent of funds appropriated for title VI, ESEA; specific estimates of obligations for mental retardation activities are unobtainable.

Mr. Black. Returning to the description of our activities, preventive services are those rendered as a part of programs designed to reduce the incidence of mental retardation.

The major activities in this area are carried on under the maternal and child health programs authorized by the Social Security Act and the preventive services programs under the Public Health Service Act.

Research provides our hope for the future in mental retardation, through prevention and early treatment. In 1970 and 1971, the availability of the Rubella vaccine, which HEW supported through research, vaccine production and wide dissemination, should prevent repetition of the tragedy of the 1964 Rubella epidemic when an estimated 9,000 babies were born retarded.

Basic nutritional research has revealed the harmful effects of malnutrition on the physical and behavioral development of children and should provide future guidance in diet supplementation for both mothers and children as a further means of prevention.

The Department is also expanding and improving its programs of family planning research and services, since both the spacing of children and the number of pregnancies can affect the incidence of mental retardation.

State health departments, crippled children's agencies, and State welfare agencies use funds provided under the Social Security Act for activities designed to: increase the health and welfare services available to the retarded; enlarge existing mental retardation clinics by adding clinic staff; increase the number of clinics; begin evaluations of children in institutions; extend screening programs; provide treatment services for physically handicapped retarded youngsters; increase inservice training opportunities; and provide homemaker and other care services for the mentally retarded.

The mentally retarded receive a variety of services under our vocational rehabilitation programs in the form of medical diagnosis, physical restoration, counseling and testing during the rehabilitation process, assistance in job placement and followup to insure successful rehabilitation.

Training programs form an integral part of most of the mental retardation programs of the Department. These programs include support of professional preparation in the following areas: research training in the basic and clinical biological, medical, and behavioral sciences; training of professsional personnel for the provision of health; social and rehabilitative services for the mentally retarded; inservice training of workers in institutions for the mentally retarded; training of teachers and other education personnel to provide education for mentally retarded children; and training of personnel in recreation and physical education activities for the mentally retarded and other handicapped children.

It is against this background of activities in the Department, Mr. Chairman, that I now want to return to the question of extending and amending the particular legislation now before this committee. And we must begin, I think, by looking at certain economic considerations.

The first of these is that even now the programs conducted under this act are funded at substantially less than the authorized level.

Authorizations for fiscal year 1969 were $60 million, while appropriations were $29.5 million. For the present fiscal year, the authorizations total $84 million. The administration has requested $20 million, and the House appropriated $24 million.

I might point out here that that administration request of $20 million this year is approximately the same as the administration request of the previous year, which was $20,900,000.

It must be constantly remembered, however, that the total Federal effort is not to be measured by these figures but by the $366 million committed to training, research, and services for the mentally retarded—of which the funds spent under this one program are only a fraction.

Second, I want to say in all candor that in our opinion substantial new sums of money are not likely to be available for this program, among many others, in the immediate future because of the budgetary constraints necessitated by the urgency of stemming inflation.

This administration is firmly committed to control of this inflationary situation by using all tools at its disposal, including strict control of governmental expenditures. Under such constraints, the requirement that we choose our priorities among a host of desirable programs becomes ever greater.

The administration, therefore, has considered legislation for extension of the mental retardation program in the context not only of the needs of the program itself but also the larger administration legislative program and fiscal policies.

In this context, we believe that to hold out the hope of vast increases in expenditures for this portion of the program would raise false expectations.

Furthermore, Mr. Chairman, one of the major goals of this administration is to consolidate and simplify Federal grant programs.

It should be obvious from the earlier summary of HEW programs in the area of mental retardation that we want to undertake a broad gage review of all these programs before committing this administration and the American taxpayers to vast new expenditures in any individual program on a piecemeal basis.

A basic point I would like to make, Mr. Chairman, is that the administration is committed not only to the continuation of mental retardation programs and services but to strengthening the quality of the projects funded and to prevention of mental retardation wherever possible.

We will move ahead as fast as fiscal constraints will permit, but inevitably these constraints force choices among alternatives.

In these circumstances, therefore, we believe it is desirable to amend the Mental Retardation Facilities Construction Act in ways that would simplify it through consolidation, make it more flexible, and encourage the use of available resources where they will be most effective.

With these objectives in mind, Mr. Chairman, we have some serious reservations about S. 2846, which was introduced by members of this committee.

It does embody some principles with which we are in accord. Although it contains at least two programs, it moves significantly in the direction of unified grants, a direction with which we agree and are proposing to you today.

The bill also places substantial responsibility on the States, something to which this administration subscribes, although the cumulative effect of the rather detailed State plan requirements considerably limits the exercise of responsibility that the bill would appear to give to the States.

If funds of the magnitude authorized in the bill were likely to be made available, we perhaps could reconcile our differences on other points. However, with present fiscal constraints, we must think in terms of funding near present levels—not a severalfold increase—for the foreseeable future.

At these levels, we do not believe that the machinery provided by the bill can be relied on to get available dollars to the places, for the purposes and at the times that they are most needed.

Regardless of budgetary considerations, the concept of developmental disability in the bill gives us concern. Unlike the present focus on mental retardation and associated neurological conditions in existing law, S. 2846 would apparently cover any chronic defect or condition. Many of these are now the subject of other programs—crippled children's services, vocational rehabilitation, and so forth.

Apart from the problems of overlap and duplication, we are not convinced that enough has yet been done in the field of mental retardation to warrant taking the central focus off mental retardation and closely associated conditions in this particular legislation.

As for the problems of duplicating and overlapping authorities to which I just referred, they are serious, indeed because the scope of title I of S. 2846 is far broader than the program it replaces.

As defined, a "developmentally disabled" person could include virtually all seriously emotionally disturbed children and a great number of mentally ill adults whose disorders can be said to have originated at some time in their childhood. These individuals are now eligible for care under the community mental health centers program, which we feel is better designed to meet their needs.

Moreover, the effect of separating a particular group of mentally ill individuals—preponderantly children—from the programs available for other such persons would be the creation of a new and highly specialized mental health program, set apart from the programs provided by the community mental health center for other family members. This is inconsistent with the public health family treatment approach favored in this country.

Even if services under the proposed developmental program and under the existing community mental health centers program were offered under one roof, the many differences in the requirements for each program would lead to great difficulties of administration.

For the above reasons, we do not recommend enactment of S. 2846.

Instead, we propose a consolidated grant approach which would replace the present program of grants for construction of mental retardation facilities, grants for construction of university-affiliated facilities and grants for initial staffing of community mental retardation facilities with a single 3-year program of grants to public or nonprofit private agencies for facilities and services for the mentally retarded, including such things as:

> Provision of services for the mentally retarded (operations grants);
>
> Construction of mental retardation facilities;
>
> Development and demonstration of new or improved techniques for provision of services for the mentally retarded;
>
> Manpower development;
>
> State and local planning, administration, and technical assistance.

Under this program the Federal share would not exceed 75 percent of the cost of new projects, including construction, except in poverty areas, where 90 percent will be permitted.

This program would provide for joint funding arrangements with other Federal programs.

It would provide operational support to those recipients who have received commitments for future support under the existing law.

Assurance would be provided that there would not be less Federal funds for all types of projects in a State than were alloted to it for fiscal year 1970 for construction of community mental retardation facilities.

States would also be given an opportunity to review and comment upon projects in their jurisdiction before grants were made.

The administration's legislation, we believe, will provide the simplification and the flexibility I said earlier are needed if available resources are to be used where the need and the opportunity for effectiveness are greatest.

And I think it should be emphasized here, Mr. Chairman, that the mental retardation problem is not one that is spread evenly among the States or the population. On the contrary, we now know that three-fourths of the Nation's retarded persons are concentrated in poverty areas.

Obviously, this startling fact must be taken into account in all efforts to deal with the problem, as the President's Committee reminded us earlier this year when it reported:

> No recent finding about mental retardation has had greater impact than the discovery that retardation rates soar in urban and rural low-income areas. No estimate of mental retardation incidence in such neighborhoods is less than twice the national average.
>
> One inner-city count of retarded persons found one-third of the total population in a several-block area functioning at retarded achievement levels.

Unhappily, however, since the inception of the community mental retardation facilities program in 1963, it has become increasingly clear that those in greatest need of community-based service, the urban and the rural poor, have been the least able to effectively organize, plan and raise sufficient funds to compete for Federal grant support.

Despite the fact that development of adequate mental retardation services in poverty areas is recognized as of highest priority at Federal, State, and local levels, development of such services for these areas is proceeding at a rate much slower than is to be desired. Inability to assure matching funds is a major cause. Priority of need means little in the face of the necessity to demonstrate adequate financial resources.

An early study of 166 projects showed that only 12 facilities were located in poverty or disadvantaged areas—which can hardly be called reassurring in the light of the knowledge that 75 percent of all the retarded persons are located in such areas.

Among the primary reasons for this situation have been (1) inadequate State and local funds to match the Federal support, which has a maximum of 66⅔ percent; and (2) lack of adequate operational support.

Preferential matching for both construction and operating costs will do much to provide the needed incentive and assistance for the establishment of services in these underprivileged areas.

Extended length of time of Federal participation in operating costs will provide a longer period of availability of close Federal-State-local partnerships and meaningful technical assistance to these local programs.

In conclusion, Mr. Chairman, I would like to point out that the President's Committee on Mental Retardation has identified several areas in which concerted public-private effort can bring significant progress in mental retardation—

> Increasing the availability of mental retardation services, particularly in the urban and rural low-income, disadvantaged neigh-

borhoods in which some three-fourths of the Nation's mental retardation is found;

Development of more and better manpower recruitment and training programs for work with retarded;

Better, more imaginative use of existing resources at all levels, as well as broader realization and use of the resource that the retarded themselves represent;

Development of more public-private partnerships in mental retardation programs, services, and research.

We believe that the administration's legislation, which we hope to submit quite soon, will help focus in on these needs, and we urge its thoughtful consideration by this committee.

That concludes our prepared statement, Mr. Chairman. My colleagues and I will be glad to answer any questions which you may have.

Senator Kennedy. Thank you very much.

You mention at the conclusion of your testimony that the administration does plan to introduce legislation. Realizing that the present legislation expires next June, can you give us any idea as to when we might expect this legislation?

Mr. Black. I would hope this week, Mr. Chairman. Next week sometime at the latest.

Senator Kennedy. So that we can expect administration proposals within these next 2 weeks?

Mr. Black. Right.

Senator Kennedy. As I gather, your proposals will emphasize your recommendations for increasing the availability of services for the retarded in urban and rural low-income areas, manpower recruitment and training programs, more imaginative use of existing resources and the development of public and private partnerships.

Is there anything you wish to say in elaboration of those points at the present time?

I am thinking, particularly, about manpower development programs.

Mr. Black. I think the only thing, Mr. Chairman, is that the administration proposal will, by consolidating these various programs we now have into a single project grant approach, give us what we think is flexibility to put available Federal resources in this program where the need appears to be greatest and where the promise for maximum return on this investment appears to be greatest.

Senator Kennedy. Would you please elaborate on your reasons for preferring the project grant approach over the formula grant approach?

Mr. Black. The first reason for our point of view on favoring a project grant approach rather than formula grants here is the availability of dollars. When you are talking about funds in the range of the present appropriations, we feel that to spread money out through a formula grant approach alone is not as effective as it would be if you had much larger sums of money.

Secondly, as I indicated, this particular problem, unlike some others that we are dealing with, is not one that is spread evenly among the States or among the populace because we do have such a concentration of mental retardation in the poverty areas.

We have seen with the present law we are not reaching those areas the way we should be. So, we want to provide more flexibility for targeting in on those areas.

Senator **Kennedy**. Of course, as I understand it, the formula in the present law requires that at least $100,000 must go to each State. Is that correct?

Mr. **Black**. The minimum required under the present legislation is $100,000. There is a provision, of course, for transfer of that money to a neighboring State for facilities to serve residents of both States. There have been, I think, very few transfers—about $155,000 in the past years.

Here again, our experience shows that at this point, anyhow, the capability of the States in developing these programs and making use of these funds varies widely.

Senator **Kennedy**. Do any of the other representatives of the Department wish to make comments here before we get into further questions?

Mr. **Black**. I don't think so. We will be glad to try to answer your questions.

Senator **Kennedy**. Let me say here how pleased I am to see Dr. Edward Newman here. He has had a long association with Massachusetts.

Before coming to Washington, Dr. Newman served as the coordinator of the Massachusetts mental retardation planning project, and as the executive director of the Massachusetts Vocational Rehabilitation Planning Commission. We in Massachusetts are proud of the progress we have made in mental retardation, and I know that you, Dr. Newman, have had an important influence on the success of those programs. I am pleased that a person of your experience and qualifications has been appointed Commissioner of the Rehabilitation Services Administration. I welcome you on your first appearance in your new position before a Senate committee, and we look forward to working with you in the months and years to come.

I would like to ask Dr. Newman to describe the success or failure of the 1963 legislation. What progress has been made in terms of the limited kind of resources that were available under that act? What has been the record?

Mr. **Newman**. The record has been both good and in some places not so good. I think that one of the problems with the current legislation, which your bill as well as the administration bill tries to get at, is not separating out the construction in the way that it was separated out in the current bill so that you have services and construction and training and the other approaches and the possibility for a broad approach to resource development for the retarded.

I think, in that sense, both the administration proposal and your proposal are similar.

One of the important issues here is how a State utilizes the funds or doesn't utilize the funds to the best advantage, and I think that the position of the administration in this instance is that some more flexibility, if we are going to be in a situation of considerable fiscal restraint, should be exercised in using the little money that we have for encouraging the States and the voluntary system, in a planful way to make best use of this money.

Senator **Kennedy**. How have the States used the limited money available under the present law? Haven't a number of the States done a reasonably good job in terms of providing facilities and other kinds of services?

Mr. **Newman.** I can only speak from my experience in Massachusetts in this instance, having been on this job just since October 1. A number of things happened in Massachusetts which I think might be considered to be exemplary in this regard.

One of the things which happened was that as a result of statewide planning, from the very outset of that activity a few years ago, retardation was looked upon not as a private domain of any single department in the State but was looked upon as an interdepartmental problem.

It was viewed as a problem which had to do with the partnership between the public and the private sector as well. As a result of statewide planning activities is was felt very important to have in the Governor's close orbit, in the Executive Office for Administration and Finance actually, an office or bureau of mental retardation which would review all the retardation activities of the State and all the departments, and try in a planful view, not to proliferate another bureaucracy but to look at the development of the programs for the retarded across the board in the public and private sector, which they are doing right now. I think it is a significant development.

I would add one other thing. In Massachusetts with respect to the construction activities under this act an opportunity was grasped—I am not sure whether all States grasped this type of opportunity but an opportunity was grasped—to have an assessment at the State level made of not only those facilities which would be constructed with the partial use of Federal moneys. As you know, the Federal share on construction projects in this field is very, very small, it is really seed money, stimulation money, and that is the way I think the Federal share should be used. An attempt was made to use this device of having a State council in this area to review all construction and facility improvements, and not only new construction activities but any kind of activity which would involve any facility at all.

As I say, I am not sure whether all States grasped this opportunity. Perhaps Dr. Jaslow can give you that information.

Senator **Kennedy.** Dr. Jaslow.

Dr. **Jaslow.** I think it has been variable, as has been stated before. Most States have attempted to use the original plans that they had and some States have continued these planning activities. Others have an individual project approach to the matter. At this point in time it is rather difficult to say which might be better.

Senator **Kennedy.** I know you have been very involved in this program since 1967, as I understand it.

Dr. **Jaslow.** That is right.

Senator **Kennedy.** What have you found in terms of progress by the States? What they have been doing?

Dr. **Jaslow.** I think there has been considerable progress in the sense that there has been a more concerted effort than they had accomplished as a result of the original activities and the interest in this area.

The question, of course, comes up as to whether they have always been able to put their interest and efforts in the areas which have had the greatest need or whether they have put them in areas in which there have been funds available for matching.

Mr. Newman. I would say, and I wonder whether Dr. Jaslow would concur with this, Senator, that there has been difficulty in States following their priority system for the reasons which Mr. Black developed in his testimony.

I think that here, whichever way we go, we have to make sure that the impoverished areas have the kind of technical assistance and are able to develop the capability to participate. I think this is a Federal as well as a State responsibility, to make sure that those areas which have, and rightfully should have, the top priority, get the kind of assistance to make sure that they are able to come up with proposals and workable plans for their areas.

Senator Kennedy. Dr. Jaslow, could you tell us what the real needs are in terms of the field of retardation? I know it is difficult to draw a distinction between training programs and research but I would like to know what the most critical needs are today for the mentally retarded and those with other developmental disabilities?

Dr. Jaslow. Again, that would vary in different locations. Certainly there is a need in many of these areas, training, research, and services. The extra or intensified concern and approach to early intervention and prevention would certainly be a productive area. Earlier intervention can also prevent many of the secondary and tertiary effects which produce an increased economic drain both on the family and on the community.

So this leaves us, of course, with the need to train people to recognize this, to know what skills to utilize and who to turn to. This falls into the same pattern of having families, parents, expect that something can be done and providing them the support to do so.

I would not want to discount either the need for research in the sense that we are constantly finding new approaches to many of these problems which reduce both the manpower and financial need through reducing the degree of disability of many of these individuals.

In more sophisticated areas generally I would say, and where people have availability of the more sophisticated services, their needs are more likely to be met.

In less sophisticated areas where people do not have the availability of these services, I think we need more of an educational program and additional services, of course, to back up the educational program.

Senator Kennedy. Mr. Black, do you wish to add anything to that?

Mr. Black. I don't think so, Senator, except to emphasize this one point on the whole question of need. This study I referred to in my testimony showed that of the 166 centers that were studied at that particular time, only 12 were in poverty areas.

Senator Kennedy. When was that study made? Are the data recent?

Mr. Black. That study was in 1967. There has been no comparable study of that kind since then, although I understand Dr. Jaslow's impression is that if we made another study now we would get comparable results.

We did complete a separate study more recently in model cities neighborhoods that showed that of some 300 construction projects, 20 percent were in model cities neighborhood areas, which means one-fifth of the total projects.

Yet we have 75 percent of our target population in these poverty areas. Again, I just want to emphasize this area of need, particularly in view of the wide range of programs that we have in the Department. We think it important to tool this program up in such a way right now that we can target it in on needs that we know are not being met otherwise.

This is one very glaring need in these poverty areas. What we want to do is to make more flexible, give more support if necessary, give planning money to help them get started, give them a greater percentage of support for a longer period as the case may be in individual circumstances.

Meanwhile, I want to emphasize as strongly as I can our interest in reviewing this total program in the Department. As we have said before this committee on other occasions, there are a lot of things down in HEW that we are trying to take a hard look at.

In my experience there I don't know of anywhere the need is greater than in this particular area because we do have so many programs in different parts of the Department—in the Office of Education, in HSMHA, SRS, they just range all over the lot.

We are trying right now to make some studies of those various programs in conjunction with some other longer range studies we are making.

Senator **Kennedy**. Mr. Black, in your testimony you indicated that little or no increases would be proposed by the administration for various health programs.

You mentioned priorities, which imply increases in some areas. Is mental retardation one of your priorities?

Mr. **Black**. I think certainly mental retardation is a priority. I further said we want to devote as much money to it as our fiscal resources will allow. I would like to make a couple of points in that respect. One is that there are certain built-in increases here in the cost of our programs, as indicated by the fact that this year we are spending $77 million more than the comparable figures last year.

Now, much of that is for matching grants for vocational rehabilitation, for medicaid programs, help to the retarded in that way, things that we have no control over because they are built-in costs.

Beyond that we are putting some money into some other aspects of the mental retardation program. For instance, we have programed more money for rubella vaccine. In addition, we are proposing some other programs which certainly cannot be said to be unrelated to this one.

One of the things we are trying to do, as you know, is come up with, in conjunction with the Congress, a new welfare program. We have made our proposal, which is going to be an expensive program, adding at least $4 billion a year to the present cost.

The hope here is that we are going to break the cycle of poverty and rescue families from the dependency and poverty morass that they are in now.

When you realize that the incidence of mental retardation is so high in the poverty area, I think you have to take this into consideration in our total effort.

I would like to have Dr. Steinfeld comment on this, too, in respect to priorities.

Dr. **Steinfeld**. I think one must distinguish between prevention and care for those who are already mentally retarded. Among the priorities clearly is family planning. Since the incidence of mental retardation is much higher among children who are born very rapidly year after year, rather than more widely spaced, particularly in poverty areas, family planning funds and information and better family planning should result in the decrease in the number of mentally retarded children born.

The fact that many women who have these children have never seen a physician during the period of their pregnancy and have not had prenatal care is a significant problem.

I think the emphasis on comprehensive health services and providing prenatal care to pregnant women should again improve or prevent the problem. Improving the nutrition of the pregnant mother and newborn child, the child during the first 5 years of life, which is another of the health aspects which we are emphasizing in this Administration, I think should also move in the direction of reducing retardation.

And, as Mr. Black mentioned, the rubella vaccine and prevention of other infectious diseases, along with increased emphasis in NICHD on research in other areas such as genetic counselling, which is really a new field and getting results, all contribute to the health portions of this program, aside from the family assistance program which is another approach to the same overall problem.

Senator **Kennedy**. In terms of priorities, I am particularly interested in your views as to facilities and training programs. I know you were not trying to be all inclusive in your examples.

Dr. **Steinfeld**. Ideally, of course, one would like facilities to be near home in these areas. Once again by having project grant money available and providing it where the need is greatest would seem an appropriate direction to go.

Funds for facilities are available in the administration proposal which you will be receiving shortly. Training is again a problem, research training which must be emphasized, and service training which is also necessary in this area. I think we have a deficit of trained professional personnel in the health area all across the board. We must emphasize manpower.

Senator **Kennedy**. Mr. Black, would you describe the number of applications and the demand for the funds that now exist? Can you give us any figures in this area?

Mr. **Black**. I would like to have Dr. Jaslow give those figures.

Dr. **Jaslow**. Under the initial staffing program there were about 300 applications for the first year of operation, requesting about $15 million. We funded about 257 of them with the available money of $8,350,000. We do not have applications as such for construction but, of course, there is a backlog of need.

There is a preliminary list from the State agencies which gives us an idea; about 318 projects are on the drawing boards ready to come in.

The Federal share would be—I don't have that figure at the moment but it would be considerable, somewhere around $100 million.

Senator **Kennedy**. Are these facilities that are on the drawing boards now?

Dr. **Jaslow**. Facilities that are either on the drawing boards or for which groups have evidenced some interest in developing.

Then in the area of the university-affiliated centers there are approximately 55 institutions which have or are developing projects—

about eight or nine projects that are just about ready to be reviewed if funds are available, and there is one project that is approved but not funded. There are about 28 that are in the process of being developed.

Senator Kennedy. How much would that be in terms of a financial commitment by the Federal Government?

Dr. Jaslow. I would have to figure that up, sir, and supply it for you later.

(Information subsequently supplied for the record: $125 million.)

Senator Kennedy. Dr. Newman what is the length of time now that a child must wait to go into a State facility in Massachusetts?

Mr. Newman. Miss Doris Fraser would have the up-to-date number on that.

Senator Kennedy. I see Miss Fraser in the audience. She is the head of the Bureau of Retardation in the Governor's Planning Office in Massachusetts. Can you give us that information, Miss Fraser?

Miss Fraser. We have approximately 700 waiting for admission to our State schools right now.

Senator Kennedy. Is that in Massachusetts?

Miss Fraser. Massachusetts.

Senator Kennedy. 700 waiting?

Miss Fraser. That is right.

Senator Kennedy. What is the length of time they have to wait?

Miss Fraser. They wait anywhere from 6 months to 10 years.

Senator Kennedy. Is that in Massachusetts you are talking about?

Miss Fraser. Right.

Senator Kennedy. Why does one person wait 6 months, and another 10 years?

Miss Fraser. I am not speaking for the department of mental health itself. I am not in the department of mental health, I am in the Governor's office. But the general practice that I have been familiar with there is that there are many times when parents will put their names on the waiting list in anticipation of the child growing older or themselves growing older and not being able to manage the child. The person's name stays on the waiting list until such time as the parent again makes a decision or places more pressure on the department for admission.

But there is a greater and greater effort in each of the State schools where we have a community evaluation and rehabilitation clinic to plan on care in the community and this is really taking hold in Massachusetts now.

But there are still many people who need institutional care and do not receive it.

Senator Kennedy. How long is the waiting period for a parent who really needs to get his child into a State facility? Can you distinguish in your statistics between those who are really in need and those who are just putting their child's name on the list in anticipation that there may be a need in the future?

Miss Fraser. Emergency care? I think in all instances you would find a response to immediate emergency care. There has been an effort to centralize the admissions list. There has been an effort to handle on an emergency basis people who really need relief, emergency relief.

This kind of administration was instituted by Dr. Burton Black in

Massachusetts who consolidated the waiting lists in State schools to set up a very careful administrative policy about emergency admissions.

Senator **Kennedy**. Do you know what is the average waiting period in other States, such as New York?

Miss **Fraser**. I am not familiar with New York. I have been spending more time on the problem of rewriting our laws pertaining to admission, commitment, retention, and discharge.

I think generally across the country most of our laws which pertain to people in institutions are basically not constitutional.

We have work to do to upgrade the laws pertaining to incarceration of the retarded. This is a major need, plus guardianship laws in the country.

Senator **Kennedy**. Thank you very much for this information, Miss Fraser.

Dr. **Jaslow**. I think basically the most on any State waiting list totals around 31,000 but it is not an accurate figure.

It also includes those who are waiting, particularly where there are elderly parents, in case something should happen.

It also does not include others who frequently don't apply because they feel the wait is too long. The difference in the admission rate is also due to the fact that today more and more of the institutions are subdivided into special units and there may be an opening in a particular unit more frequently than in another particular type of unit.

In other words, among an adolescent group where there is likelihood of vocational employment, there may be a greater turnover than in another age group or handicapped group.

Senator **Kennedy**. Even assuming there are special difficulties with respect to certain types of facilities, what is the average waiting period for parents before they can get their retarded children into a State institution?

Dr. **Jaslow**. I would have to repeat what was said before, anywhere from a few months up to years, depending on the State and the area.

Mr. **Newman**. May I say the average time is too long, whatever it is. I think one of the hopeful things that has happened over the last few years has been the development, stimulated by the Federal Government, of activity by the voluntary groups, and the kind of State planning efforts that you have been hearing a little bit about this morning which have stimulated the States in both the public and people begin to see the alternatives to institutionalization.

Here is the promise of the future. One of the things that we have begun to find is that when certain kinds of supportive services become available in a community to sustain a person in his home, the waiting list problem has a tendency to begin to disappear in the sense that people begin to see the alternatives to institutionalization.

I don't know whether there has been enough experience to document this, nor am I aware of any specific studies in this area. But, I do know, in talking to parents of retarded children, that when a community facility, a day-care type facility, and other kinds of supporting services do begin to appear within an hour's travel distance, for example, then the peace of mind which results frequently takes away the pressure on the waiting list in some of our institutions.

Senator Kennedy. Has the length of the waiting period changed in the last 5 or 6 years?

Dr. Jaslow. I would say so. First of all, there has been greater use of other facilities and services, not just for those on the outside but also with transfers or utilization by those who are already residents.

I would say that between the appreciation of alternate means of services, the use of other types of residential services and community services, the period of time people have to await admission in many areas has decreased as they have developed this broadened spectrum of services.

Senator Kennedy. How do we decide how effectively our Federal expenditures are meeting the problem?

Mr. Black. This is one of our problems, Senator, because I think we are not sure which are the most effective. As I indicated earlier, these activities are spread so far over the department that one of the things that we are very seriously engaged in and want to do more is to try to evaluate our various programs in the field so that we can see which ones are on target and which ones might be consolidated.

A little bit of history might be interesting to you. Mr. Kelly, our Assistant Secretary-Comptroller, told me that back in the days when Mr. Fogarty was chairman of the Appropriations Subcommittee on the House side, that on a plane trip at one point he read a magazine article on retardation in which Cardinal Cushing was quoted as having said he considered retarded children as exceptional children.

Mr. Fogarty got very interested in the whole problem and eventually, according to Mr. Kelly, in the Appropriations hearing, everybody who came up before Mr. Fogarty was asked, "What are you doing for retarded children? What are you doing for these exceptional children?"

The result was that we had a lot of programs built up all over the Department. We do have one coordinating mechanism, as you know, the Secretary's Committee on Mental Retardation, which is a committee which includes the heads of the agencies dealing with retardation programs, but it is not an operational group.

Frankly, as a new administration, we feel that the overall evaluation and coordination of these different programs leaves something to be desired, which is why I say that before we commit ourselves to spending vast new sums on any one program on a piecemeal basis we would like to try to get a better idea of the whole picture.

Senator Kennedy. Mr. Black, last July you came before this subcommittee to testify for the administration on the mental health bill. You made the following statement:

> To achieve our goal the Administration has a basic objective, first, of not proliferating and adding to existing grant authorities; second, of employing broader purpose authorities so that there is flexibility to respond as conditions and needs change, so that the localities and the States themselves may have a voice in using the Federal funds.

Do you think that statement is consistent with your position this morning in favor of project grants, rather than formula grants?

Mr. Black. I think it is consistent, yes. We are trying to consolidate these various authorities into one authority. The only place in which you might say it is inconsistent goes back to the question you asked earlier as to why we prefer project grants instead of formula grants.

My answer was that in this case we are dealing with a much smaller program dollar-wise than we were in community health centers.

Second, we have a problem here which is concentrated in various specific areas, not spread evenly among the States. I think what we are trying to do is consistent with our overall administration philosophy in consolidating these where possible and making them as flexible as possible.

As I point out in my testimony, as you will see when we send up our bill, we will give the States the authority and the opportunity to review and comment on any project grant.

We are not going to make them all right here in Washington in disregard of what the States think are important.

Senator **Kennedy**. Turning to another issue, would you tell us why you feel the definition should be limited to mental retardation, rather than including other developmental disabilities as well?

Mr. **Black**. Not anything further than what I said in my statement. Perhaps one of our professionals would like to comment on that. The feeling was that again we are going to be diluting the effectiveness of this program by spreading the resources that we have to these other handicaps, and second, that we would be overlapping and duplicating programs which exist in other parts of our Department.

Maybe Dr. Jaslow, Mr. Newman, or Dr. Steinfeld would like to comment.

Mr. **Newman**. I would say, Senator, that if the fiscal situation does remain near present levels, then with respect to appropriations, I think the moneys that are spent for services, construction and for training, for these types of activities, should probably be limited under the more restricted definition.

I would add, though in those States where we have evidence that the States can put their programs together in such a way that their programs can begin to take advantage of the moneys available under other programs of the Department or other departments of the Federal Government or of the State government or with the use of voluntary funds, so that we don't have a proliferation of programs but a pulling together of funds; in these instances, moneys could be made available to more individuals than those now under our definition. These types of arrangements should be encouraged. So I would think, for example, that some funds might be used for planning purposes to encourage these arrangements. But I would make a distinction between that type of planning activity and the actual expenditure of moneys for services.

Dr. **Steinfeld**. I think there are several ways to approach this. One approach is to see to it that the facilities and the personnel who are best trained to provide a certain kind of care are utilized. Developmental abnormalities might include orthopedic difficulties, difficulties in kidney development, and a whole series of medical problems, the treatment of which might be provided by other medical specialties and other kinds of personnel from those appropriate to retardation-related conditions.

Obviously, it is possible for a child to be born perfectly normal without a developmental abnormality and yet because of trauma in an accident, because of tuberculosis, meningitis, or other infectious disease, become mentally retarded because he has certain brain cells damaged, and regress. Therefore, developmental difficulty would not subsume all of the problems with which we hope to cope. I think we would do this along functional lines using facilities and personnel best trained to handle the problem.

Senator **Kennedy**. Senator Dominick?

Senator **Dominick**. Mr. Black, I apologize for not having been here for your whole testimony. I will read it with care and I have scanned it. I have a couple of questions.

My recollection is that the present authorization for staffing of community mental health centers goes down as the time goes by.

In the proposed bill, I don't know whether you have it ready yet, in your proposed bill what are you doing about staffing?

Mr. **Black**. We are leaving that, Senator Dominick, as flexible as we can. Under the present law, as you know, the arrangement is much like that for community mental health centers. It is a 51-month period of staffing support with a decreasing amount each year.

Our thinking is that in the legislation we will submit we want to leave ourselves some flexibility in this and permit, as each individual case is considered, a longer period of staffing and a greater amount of support if necessary in that individual case.

One of the things we have been discussing this morning is the special need for these facilities in poverty areas. Apparently one of the things that has happened here is that the areas which have had the most resources came in first under this program because they were able to meet the present matching requirements and got their centers, and the others did not.

So our plan is to provide flexibility in this so that if necessary it could be longer and varied, particularly in poverty areas where we are going up to a maximum of 90 percent.

Senator **Dominick**. Theoretically the idea of starting out with some Federal funding and asking the localities to match and then to have it on a decreasing basis once it gets started would seem to make some sense.

The difficulty, however, is that almost every community starts relying on the Federal funding almost immediately and then when the decreasing amount comes along they find themselves having real trouble trying to replace it.

In some cases, I know in our areas, and I am talking about the Rocky Mountain States as a whole, not just Colorado, they have found that they simply can't keep these things going over a long period of time.

Whether this is lack of interest on the part of the localities or what it is I can't say but it is a problem.

I bring that up so that it can be thought of while you are getting your own legislation ready.

Mr. **Black**. The problem is one we recognize. Of course, in the community mental health centers we have had enough experience so that some of these centers are near the time when the Federal funds are going to expire and we know on the basis of this experience that what you say is true, that the local support that we expected has not been forthcoming.

So, we proposed, and the legislation already before this committee proposed, that the period be extended to 8 years rather than the present 51 months.

Now in the case of the mental retardation facilities we have had a much shorter experience so we are not prepared to say that the centers which have already been funded are going to need a longer period than 51 months.

Some may, some may not. As we said here a few minutes ago, one of the encouraging things that has happened is that with the stimulus of Federal support, not just in this program but in a wide range of activities, there has been a lot more State and local activity.

We would hope that with this kind of stimulus, as centers are developed, they will be able to sustain themselves after a period with State, local and some private support without Federal support from now on.

Our concept still is that this should be seed money to stimulate these.

Senator DOMINICK. My opinion is that the more local responsibility on the States and local communities with resources to help them, the better off we are.

It occurs to me that maybe we are getting close to the time where we ought to say, "Look, we have outlined this program in this way and if you don't want to take up this responsibility, things are tough all over, you are going to have to fund it on your own or you have had it."

Now this is going to make a lot of people very angry, no question about that. The question is how else can we get this done unless we take a fairly firm stand?

Mr. BLACK. I think the problem with the approach you have outlined there is one we were discussing earlier, which is that the area of greatest need for these facilities is in the poverty areas where three-quarters of the retarded persons can be found. Yet we have seen that up to now only a small fraction of these facilities have been developed in those areas because in many cases they lack even the funds to plan these centers, much less to come up with the kind of support that is required under the present legislation.

So, what we are trying to do and we concede it will be administratively difficult in some ways, is to build into the legislation enough flexibility so that we may adjust these requirements and the Federal role as the individual circumstances and needs change.

Senator DOMINICK. Yes, but the difficulty with that is that if we start distinguishing between areas on an income basis as to where we are going to put our funds, what we are saying is that a man who has a kid who is mentally retarded and lives in a poor area is going to get help but a person who is in the same income bracket but happens to live in a higher income area is not going to get any help.

Mr. BLACK. I think we would be saying that the man in the poverty area would get more help than the other man.

Senator DOMINICK. In case they are in equally bad shape in both areas you can't distinguish between mentally retarded kids.

Dr. STEINFELD. I think if we talk about prevention, Senator, the opportunities are much greater in the poverty areas. I think the emphasis there would be in attempting to prevent retardation rather than in the provision of services which is another part of the problem.

I wanted to say something earlier, I think your question was particularly appropriate, where a program is successful, whatever it is, where one develops a new drug successful against a rare form of cancer, patients appear from all over the place with this form of neoplasm.

In the California Health Centers Act when the facility is working well and is active it begins attracting more and more people and becomes more and more active.

It is just at this point that the Federal dollars begin decreasing. We are quite aware of the problem in meeting with the State mental health commissioners. We are working on it. It is a very acute problem. You have hit on an important point.

Senator DOMINICK. If you have a consolidated grant program and approach, which I think is something that I would like to see us work toward wherever we can, don't you immediately run into the same situation where you have the problem of some of the local areas saying, "Well, what we need here is construction funds," and another one saying, "What we need is staffing," and you get an uneven approach.

I am not saying that the uneven approach is bad but the question immediately comes up if you do it this way don't you have a situation where in some areas you will find the program is successful and in others it is not because of the difference in the ability of the local authorities to determine how the money can best be spent?

Mr. BLACK. I think you will have to some extent an uneven approach but you have an uneven problem, too. This is really what is behind our recommendation on this. We think that the needs are going to be different in various areas. We are trying to give ourselves enough flexibility here to meet them.

If you have one area which is going to need more support for one of these facilities to keep the thing from folding its doors and going out of business, perhaps we could be in a position to provide that support.

Senator DOMINICK. Let me ask you this, if I may. Assuming that we do get an uneven approach, and I think this is a fair assumption under a consolidated grant type of program, is there any provision for the dissemination of information between areas so that they will know which approaches are working in a particular area and which ones are not?

Mr. BLACK. I think that is going to be one of our responsibilities. Under the concept that still guides us in this particular program, which is the seed money concept with the Federal Government using its resources to stimulate development in the States, one of the things that we want to do and one of the reasons that we want the kind of flexibility we are asking for here is to be more able to target our money to any new approaches which any State or locality may come up with which seem to us to be especially promising so that we can give that State the encouragement it needs.

If it does work out we will want to share that with other States and localities.

Senator DOMINICK. Thank you, Mr. Chairman.

Senator KENNEDY. Thank you very much, gentlemen. We appreciate your testimony. I am grateful to each of you for coming here this morning to present the administration's testimony. In light of the issues that have been raised, I believe that it may be helpful to request additional information from the Department. I would like to submit some supplemental questions to you, and I hope that the questions and your replies, along with your prepared statement, may be printed at this point in the record.

Mr. BLACK. Thank you, Mr. Chairman.

(The prepared statement of Mr. Black, and covering letters, and the material referred to, follow:)

PREPARED STATEMENT OF CREED C. BLACK, ASSISTANT SECRETARY FOR LEGISLATION, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

Mr. Chairman and Members of the Subcommittee, it is a privilege to appear today to testify on the progress that has been made under the Mental Retardation Facilities Construction Act and proposals for its extension and amendment.

This legislation, as you know, was initiated in 1963 with the objectives of stimulating the development of needed manpower, research, and a network of facilities for the delivery of services to the mentally retarded. In the years since 1963, progress toward those goals has been significant.

Under the community mental retardation facilities program, (Part C), for example, 297 projects have been approved. When completed, they will make available modern and efficient facilities to provide services to 30,000 persons who were not being served at all and improved services to another 45,000 persons. When the present authorization expires on June 30, 1970, about 67 other facilities will have been funded, which when completed will provide services to 15,000 more persons.

Comparable progress has been recorded under the program of initial staffing grants for community mental retardation facilities, which was added to the Act by the Mental Retardation Amendments of 1967. These grants are available to assist in the initial staffing of both new facilities and new services in existing facilities. To date 237 projects have been funded, providing support for staff to serve over 60,000 retarded. It is expected that by June, 1970, when the present authorization expires, 468 projects will have been funded, providing staff to serve more than 120,000 retarded in their home communities.

The third major effort financed under this Act is the University-Affiliated Facilities Program (Part B), which provides grants to assist in the construction of facilities affiliated with universities or colleges which offer interdisciplinary training based on exemplary models of comprehensive services to the mentally retarded.

The University-Affiliated Centers are a major resource for training professional and technical personnel needed to work with the mentally retarded, such as physicians, social workers, nurses, psychologists, special educators, therapists, and rehabilitation specialists.

Through 1969, eighteen projects have been approved and funded; six have been completed and eight more should be completed within the next 12 to 18 months. The facilities are coordinating their activities with other community programs, and with State residential programs for the retarded. As a broad resource for specialized training, continuing education, and the provision of exemplary service in complex cases, they fill a role in the system of mental retardation services similar to that of the teaching hospitals in the health field or the research and training centers in the field of vocational rehabilitation.

Before turning from this brief summary of results thus far to the question of where we go from here, Mr. Chairman, I think it is important that we put this particular legislation into the broader context of our department's total activities in the mental retardation area.

As the members of this committee are no doubt aware, the Mental Retardation Facilities Construction Act is but one part of a much larger effort which spans the entire Department of Health, Education, and Welfare. The impressive scope of these department-wide activities was described in a report prepared earlier this year for the House Appropriations Subcommittee by the Secretary's Committee on Mental Retardation. With your permission, I should like to submit a copy of the complete report for the record of these hearings and summarize it briefly for the purposes of our discussion today.

The Department has responded to the needs of the retarded through a broad range of approaches which include preventive services, training of personnel, facility construction, research, education, and other supportive services.

The estimated budget requested for 1970 includes $585,169,000 for mentally retarded persons and for prevention of mental retardation with the following breakdown:

Services, Research, Education, Rehabilitation	$365, 869, 000
Income Maintenance (SRS—75,000,000; SSA—144,300,000)	219, 300, 000
Total	585, 169, 000

This estimated total of $585 million for 1970 is more than $77 million above the comparable figure for 1969. And the bulk of that increase—approximately $56 million—is for services and grants.

I would like to give you just a very brief idea of what types of activities are covered.

Preventive services are those rendered as a part of programs designed to reduce the incidence of mental retardation. The major activities in this area are carried on under the maternal and child health programs authorized by the Social Security Act and the preventive services programs under the Public Health Service Act.

Research provides our hope for the future in mental retardation through prevention and early treatment. In 1970 and 1971, the availability of the Rubella vaccine, which HEW supported through research, vaccine production and wide dissemination, should prevent repetition of the tragedy of the 1964 Rubella epidemic when an estimated 9,000 babies were born retarded. Basic nutritional research has revealed the harmful effects of malnutrition on the physical and behavioral development of children and should provide future guidance in diet experimentation for both mothers and children as a further means of prevention. The Department is also expanding and improving its programs of family planning research and services, since both the spacing of children and the number of pregnancies can effect the incidence of mental retardation.

State health departments, crippled children's agencies, and State welfare agencies use funds provided under the Social Security Act for activities designed to: increase the health and welfare services available to the retarded, enlarge existing mental retardation clinics by adding clinic staff, increase the number of clinics, begin evaluations of children in institutions, extend screening programs, provide treatment services for physically handicapped retarded youngsters, increase inservice training opportunities, and provide homemaker and other care services for the mentally retarded.

The mentally retarded receive a variety of services under our vocational rehabilitation programs in the form of medical diagnosis, physical restoration, counseling and testing during the rehabilitation process, assistance in job placement and follow-up to insure successful rehabilitation.

Training programs form an integral part of most of the mental retardation programs of the Department. These programs include support of professional preparation in the following areas: research training in the basic and clinical biological, medical and behavioral sciences; training of professional personnel for the provision of health, social and rehabilitative services for the mentally retarded; inservice training of workers in institutions for the mentally retarded; training of teachers and other education personnel to provide education for mentally retarded children; and training of personnel in recreation and physical education activities for the mentally retarded and other handicapped children.

It is against this background, Mr. Chairman, that I now want to return to the question of extending and amending the particular legislation now before this committee. And we must begin, I think, by looking at certain economic considerations.

The first of these is that even now the programs conducted under this Act are funded at substantially less than the authorized level. Authorizations for FY 1969 were $60 million, while appropriations were $29.5 million. For the present fiscal year, the authorizations total $84 million. The Administration has requested $20 million, and the House appropriated $24 million. It must be constantly remembered, however, that the total federal effort is not to be measured by these figures but by the $366 million committed to training, research and services for the mentally retarded—of which the funds spent under this one program are only a fraction.

Second, I want to say in all candor that in our opinion substantial new sums of money are not likely to be available for this program, among many others, in the immedate future because of the budgetary constraints necessitated by the urgency of stemming inflation. This Administration is firmly committed to control of this inflationary situation by using all tools at its disposal, including strict control of Governmental expenditures. Under such constraints, the requirement that we choose our priorities among a host of desirable programs becomes ever greater.

The Administration, therefore, has considered legislation for extension of the Mental Retardation program in the context not only of the needs of the program itself but also the larger Administration legislative program and fiscal policies.

In this context, we believe that to hold out the hope of vast increases in expenditures for this portion of the program would raise false expectations.

Furthermore, Mr. Chairman, one of the major goals of this Administration is to consolidate and simplify federal grant programs. It should be obvious from the earlier summary of HEW programs in the area of mental retardation that we want to undertake a broad-gauge review of all these programs before committing this Administration and the American taxpayers to vast new expenditures in any individual program on a piece-meal basis.

A basic point I would like to make, Mr. Chairman, is that the Administration is commited not only to the continuation of mental retardation programs and services but to strengthening the quality of the projects funded and to prevention of mental retardation wherever possible. We will move ahead as fast as fiscal constraints will permit, but inevitably these constraints force choices among alternatives.

In these circumstances, therefore, we believe it is desirable to amend the Mental Retardation Facilities Construction Act in ways that would simplify it through consolidation, make it more flexible, and encourage the use of available resources where they will be most effective.

With these objectives in mind, Mr. Chairman, we have some serious reservations about S. 2846, which was introduced by members of this committee.

It does embody some principles with which we are in accord. Although it contains at least two programs, it moves significantly in the direction of unified grants, a direction with which we agree and are proposing to you today. The bill also places substantial responsibility on the States, something to which this Administration subscribes, although the cumulative effect of the rather detailed State plan requirements considerably limits the exercise of responsibility that the bill would appear to give to the States.

If funds of the magnitude authorized in the bill were likely to be made available, we perhaps could reconcile our differences on other points. However, with present fiscal constraints, we must think in terms of funding near present levels—not a several fold increase—for the foreseeable future. At these levels, we do not believe that the machinery provided by the bill can be relied on to get available dollars to the places, for the purposes and at the times that they are most needed.

Regardless of budgetary considerations, the concept of developmental disability in the bill gives us concern. Unlike the present focus on mental retardation and associated neurological conditions in existing law, S. 2846 would apparently cover any chronic defect or condition. Many of these are now the subject of other programs—crippled children's services, vocation rehabilitation, etc. Apart from the problems of overlap and duplication, we are not convinced that enough has yet been done in the field of mental retardation to warrant taking the central focus off mental retardation and closely associated conditions.

As for the problems of duplicating and overlapping authorities to which I just referred, they are serious indeed because the scope of Title I of S. 2846 is far broader than the program it replaces. As defined, a "developmentally disabled" person could include virtually all seriously emotionally disturbed children and a great number of mentally ill adults whose disorders can be said to have originated at some time in their childhood. These individuals are now eligible for care under the Community Mental Health Centers program, which we feel is better designed to meet their needs.

Moreover, the effect of separating a particular group of mentally ill individuals—preponderantly children—from the programs available for other such persons would be the creation of a new and highly specialized mental health program, set apart from the programs provided by the community mental health center for other family members. This is inconsistent with the public health family treatment approach favored in this country.

Even if services under the proposed developmental program and under the existing community mental health centers program were offered under one roof, the many differences in the requirements for each program would lead to great difficulties of administration.

For the above reasons, we do not recommend enactment of S. 2846.

Instead, we propose a consolidated grant approach which would encompass the present program of grants for construction of mental retardation facilities, grants for initial staffing of community mental retardation facilities, and a three-year program of grants to public or nonprofit private agencies for facilities and services for the mentally retarded, including such things as:

Provision of services for the mentally retarded (operations grants);

Construction of mental retardation facilities;

Development and demonstration of new or improved techniques for provision of services for the mentally retarded;

Manpower development;

State and local planning, administration, and technical assistance.

Under this program the Federal share would not exceed 75 percent of the cost of new projects, including construction, except in poverty areas, where 90 percent will be permitted.

This program would provide for joint funding arrangements with other Federal programs.

It would provide operational support to those recipients who have received commitments for future support under the exising law.

Assurance would be provided that there would not be less Federal funds for all types of projects in a State than were allotted to it for fiscal year 1970 for construction of community mental retardation facilities.

States would also be given an opportunity to review and comment upon projects in their jurisdictions before grants were made.

The Administration's legislation, we believe, will provide the simplification and the flexibility I said earlier are needed if available resources are to be used where the need and the opportunity for effectiveness are greatest.

And I think it should be emphasized here, Mr. Chairman, that the mental retardation problem is not one that is spread evenly among the States or the populace. On the contrary, we now know that three-fourths of the nation's retarded persons are concentrated in poverty areas.

Obviously this startling fact must be taken into account in all efforts to deal with the problems, as the President's Committee reminded us earlier this year when it reported:

"No recent finding about mental retardation has had greater impact than the discovery that retardation rates soar in urban and rural low income areas. No estimate of mental retardation incidence in such neighborhoods is less than twice the national average. One inner city count of retarded persons found one-third of the total population in a several-block area functioning at retarded achievement levels!"

Unhappily, however, since the inception of the Community Mental Retardation Facilities Program in 1963, it has become increasingly clear that those in greatest need of community-based service, the urban and rural poor, have been the least able to effectively organize, plan and raise sufficient funds to compete for Federal grant support.

Despite the fact that development of adequate mental retardation services in poverty areas is recognized as of highest priority at Federal, State, and local levels, development of such services for these areas is proceeding at a rate slower than to be desired. Inability to assure matching funds is a major cause. Priority of need means little in the face of the necessity to demonstrate adequate financial resources. An early study of 166 projects showed that only 12 facilities were located in poverty or disadvantaged areas—which can hardly be called reassuring in the light of the knowledge that 75 percent of all the retarded persons are located in such areas.

Amount the primary reasons for this situation have been (1) inadequate state and local funds to match the federal support, which has a maximum of 66⅔ percent and (2) lack of adequate operational support. Preferential matching for both construction and operating costs will do much to provide the needed incentive and assistance for the establishment of services in these underprivileged areas.

Extended length of time of Federal participation in operating costs will provide a longer period of availability of close Federal-State-local partnerships and meaningful technical assistance to these local programs.

In conclusion, Mr. Chairman, I would like to point out that the President's Committee has identified several areas in which concerted public-private effort can bring significant progress in mental retardation.

Increasing the availability of mental retardation services, particularly in the urban and rural low income, disadvantaged neighborhoods in which some three-fourths of the nation's mental retardation is found;

Development of more and better manpower recruitment and training programs for work with the retarded;

Better, more imaginative use of existing resources at all levels, as well as broader realization and use of the resource that the retarded themselves represent;

Development of more public-private partnerships in mental retardation programs, services, and research.

We believe that the Administration's legislation, which we hope to submit quite soon, will help focus in on these needs, and we urge its thoughtful consideration by this committee.

U.S. SENATE,
Washington, D.C., November 21, 1969.

Hon. CREED C. BLACK,
Assistant Secretary for Legislation, Department of Health, Education, and Welfare, Washington, D.C.

DEAR MR. BLACK: I was pleased to have the opportunity to hear your testimony last week before the Senate Subcommittee on Health during the hearings on mental retardation and other development disabilities.

As I indicated during the hearings, there are a number of areas, many of a relatively technical nature, where I believe that supplemental information would be of value to the Committee in considering this legislation. Pursuant to this, I am submitting the attached list of questions, and I am hopeful that we may receive your replies as promptly as possible, so that we may include them as part of the printed record of the hearings.

Sincerely,

EDWARD M. KENNEDY.

ADDITIONAL QUESTIONS SUBMITTED BY SENATOR EDWARD M. KENNEDY TO THE HON. CREED C. BLACK, ASSISTANT SECRETARY FOR LEGISLATION

1. Will you please provide us with a table of State allotments of construction funds under PL 88–164, Title I, Part C based on the $12 million made available for fiscal year 1969, along with the allotments that will result for fiscal year 1970, based on the $8.031 million that the Administration is currently requesting?

2. The language of the present Act states that in setting the formula for State allotments, the Secretary shall take into account, "... (1) the population, (2) the extent of the need for facilities for the mentally retarded, and (3) the financial need of the respective States."

(a) Would you please explain how this formula takes account of these various factors?

(b) Will you please provide us with the population and income data you used in your 1969 calculations, and the figure used for each factor for each State?

3. When you submit the list of state allotments for 1969, will you please also compute and list the amount that would be alloted to each state on a per capita basis, and the amount that would be allotted to each state on the basis of the need for facilities for the mentally retarded?

4. Will you please provide us with tables comparable to those in questions 1–3 above, for the allotment of funds under Part D of Title I of the Act?

5. It is my understanding that the Division of Mental Retardation has also been administering a project grant program of assistance to state residential institutions for the retarded, to improve their programs and provide in-service training. These are the so-called HIP and HIST programs.

(a) Will you please provide a brief explanation of each of these programs and its relationship to the programs carried out under Title I?

(b) How much money is allowed per institution for grants under each of these programs?

(c) How much would you need to fully fund these programs—i.e., to permit maximum participation by eligible institutions?

(d) Will you please provide a state-by-state table of your grant totals for each of these two programs in 1969? In the table, please list also the number of residents in the state institutions receiving awards, and the per resident awards for HIP and HIST grants in each state.

6. During the recent hearings, you pointed out that the mentally retarded benefit from a number of different programs in the Department, such as vocational rehabilitation, education of the handicapped, "medicaid," income maintenance, and so on.

It is my understanding that the mentally ill also benefit from all or most of these programs. Will you please provide us with data for fiscal 1969, and the budget estimates for 1970 on all expenditures for research, training, prevention, treatment, instruction, income maintenance, etc., for mental disorders other than *mental retardation under programs administered by HSMHA, OE, SRS, and SSA? Please provide this material as far as possible by line items comparable to those included in the table at the end of your submission on mental retardation, referred to on page 9 of the transcript of your testimony. If possible, please prepare a new table comparing the new data with the data on mental retardation.*

7. What criteria are used by the Administration to assess the relative needs of the mentally retarded as compared with the mentally ill?

8. Will you please provide the latest available data on a state-by-state basis on resident populations in state and private mental hospitals, and state and private residential facilities for the mentally retarded?

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE,
Washington, D.C., December 20, 1969.

HON. EDWARD M. KENNEDY,
U.S. Senate,
Washington, D.C.

DEAR SENATOR KENNEDY: This is in reply to your letter of November 21, in which you raised a number of questions regarding the activities of this Department in the fields of mental retardation and mental health.

Enclosed you will find materials in reply to your specific questions. We hope that this information will be helpful.

Do not hesitate to contact us again if we can be of further assistance.

Sincerely,

CREED C. BLACK,
Assistant Secretary for Legislation.

Question 1. Will you please provide us with a table of State allotments of construction funds under PL 88-164, Title I, Part C based on the $12 million made available for fiscal year 1969, along with the allotments that will result for fiscal year 1970, based on the $8.031 million that the Administration is currently requesting?

STATE ALLOTMENTS FOR CONSTRUCTION UNDER PUBLIC LAW 88-164, TITLE I, PART C

	1969[1]	1970[2]
Total	$12,000,000	$8,031,000
1. Alabama	247,101	146,091
2. Alaska	100,000	100,000
3. Arizona	100,000	100,000
4. Arkansas	140,465	100,000
5. California	916,026	541,573
6. Colorado	109,285	100,000
7. Connecticut	132,923	100,000
8. Delaware	100,000	100,000
9. District of Columbia	100,000	100,000
10. Florida	343,335	202,987
11. Georgia	287,857	170,187
12. Hawaii	100,000	100,000
13. Idaho	100,000	100,000
14. Illinois	513,046	303,324
15. Indiana	264,230	156,218
16. Iowa	145,193	100,000
17. Kansas	123,314	100,000
18. Kentucky	207,763	122,834
19. Louisiana	243,088	143,718
20. Maine	100,000	100,000
21. Maryland	189,237	111,881
22. Massachusetts	263,504	155,789
23. Michigan	440,252	260,286
24. Minnesota	197,153	116,561
25. Mississippi	185,147	109,463
26. Missouri	248,706	147,040
27. Montana	100,000	100,000
28. Nebraska	$100,000	$100,000
29. Nevada	100,000	100,000
30. New Hampshire	100,000	100,000
31. New Jersey	330,780	195,564
32. New Mexico	100,000	100,000
33. New York	834,557	493,407
34. North Carolina	329,988	195,095
35. North Dakota	100,000	100,000
36. Ohio	549,394	324,813
37. Oklahoma	148,469	100,000
38. Oregon	105,657	100,000
39. Pennsylvania	602,277	356,079
40. Rhode Island	100,000	100,000
41. South Carolina	188,434	111,406
42. South Dakota	100,000	100,000
43. Tennessee	254,368	150,387
44. Texas	651,236	385,024
45. Utah	100,000	100,000
46. Vermont	100,000	100,000
47. Virginia	266,517	157,570
48. Washington	160,332	100,000
49. West Virginia	117,421	100,000
50. Wisconsin	224,683	132,838
51. Wyoming	100,000	100,000
52. Guam	7,971	4,713
53. Puerto Rico	222,836	131,745
54. Virgin Islands	4,915	2,906
55. American Samoa	2,540	1,501

[1] Actual.
[2] Tentative.

STATE ALLOTMENTS FOR NEW INITIAL STAFFING GRANTS (PUBLIC LAW 88-164, TITLE I, PART D)

	1969[1]	1970[2]
Total	$8,358,000	$7,380,000
1. Alabama	187,845	165,865
2. Alaska	11,008	9,719
3. Arizona	75,890	67,010
4. Arkansas	106,782	94,287
5. California	696,364	614,879
6. Colorado	83,078	73,357
7. Connecticut	101,048	89,224
8. Delaware	19,590	17,300
9. District of Columbia	26,897	23,749
10. Florida	261,004	230,463
11. Georgia	218,829	193,223
12. Hawaii	31,184	27,535
13. Idaho	32,663	28,841
14. Illinois	390,018	344,380
15. Indiana	200,868	177,364
16. Iowa	110,376	97,460
17. Kansas	93,743	82,774
18. Kentucky	157,940	139,460
19. Louisiana	184,795	163,172
20. Maine	44,415	39,217
21. Maryland	143,858	127,025
22. Massachusetts	200,315	176,876
23. Michigan	334,680	295,517
24. Minnesota	149,876	132,338
25. Mississippi	140,749	124,279
26. Missouri	189,066	166,943
27. Montana	$30,925	$27,306
28. Nebraska	58,824	51,940
29. Nevada	16,632	14,686
30. New Hampshire	28,752	25,387
31. New Jersey	251,459	222,035
32. New Mexico	50,349	44,457
33. New York	634,430	560,194
34. North Carolina	250,858	221,503
35. North Dakota	29,863	26,369
36. Ohio	417,650	368,779
37. Oklahoma	112,866	99,660
38. Oregon	80,320	70,922
39. Pennsylvania	457,851	404,276
40. Rhode Island	35,054	30,952
41. South Carolina	143,248	126,486
42. South Dakota	31,108	27,468
43. Tennessee	193,371	170,744
44. Texas	495,069	437,140
45. Utah	48,919	43,195
46. Vermont	18,413	16,258
47. Virginia	202,606	178,899
48. Washington	121,885	107,622
49. West Virginia	89,263	78,818
50. Wisconsin	170,804	150,818
51. Wyoming	13,473	11,897
52. Guam	6,060	5,350
53. Puerto Rico	169,400	149,578
54. Virgin Islands	3,736	3,299
55. American Samoa	1,931	1,705

[1] Actual.
[2] Tentative.

Question 2. The language of the present Act states that in setting the formula for State allotments, the Secretary shall take into account, ". . . (1) the population, (2) the extent of the need for facilities for the mentally retarded, and (3) the financial need of the respective States."

(a) Would you please explain how this formula takes account of these various factors?

FORMULA—COMMUNITY FACILITIES AND INITIAL STAFFING GRANT PROGRAM (TITLE I, PARTS C AND D, P.L. 88–164)

Allotments to the States from the annual appropriations for mental retardation facility construction are made as follows: 2/3 on the basis of the population of each State weighted by State financial need and ⅓ on the basis of the extent of the need for mental retardation facilities, for which State population under age 21 is used. The Act provides for a minimum allotment of $100,000 to any State or Territory, other than the Virgin Islands, American Samoa, and Guam.

(b) Will you please provide us wtih the population and income data you used in your 1969 calculations, and the figure used for each factor for each State?

1969 COMMUNITY MENTAL RETARDATION CONSTRUCTION AND STAFFING ALLOCATION—POPULATION AND INCOME DATA

Basis of allocations, per requirements of P.L. 88–164, Title I, Part C:

(*a*) Total population, as estimated by the Bureau of the Census:

(1) Provisional estimated population of the United States, July 1. 1968 (Series P–25, No. 403, September 19, 1968, and unpublished data);

(2) American Samoa, Guam, Puerto Rico, and Virgin Islands, provisional estimates as of July 1, 1967, (Series P–25, No. 392, May 2, 1968).

(*b*) Facility need, as represented by provisionally estimated population under age 21 as of July 1, 1967 (Series P–25, No. 384, February 13, 1968, and unpubished data).

(*c*) Financial need, as represented by average per capita income 1965–67, published in *Survey of Current Business*, August 1968, Department of Commerce.

STAFFING ALLOCATION—POPULATION AND INCOME DATA

	Total population (thousands)	Population under age 21 (thousands)	Per capita income ratio
1. Alabama	3,566	1,531	1.4480
2. Alaska	277	141	0.8556
3. Arizona	1,670	738	1.1579
4. Arkansas	2,012	819	1.4914
5. California	19,221	7,793	.8554
6. Colorado	2,048	839	1.0142
7. Connecticut	2,959	1,150	.7980
8. Delaware	534	226	.8502
9. District of Columbia	809	315	.7628
10. Florida	6,160	2,344	1.1197
11. Georgia	4,588	1,980	1.2565
12. Hawaii	778	343	.9561
13. Idaho	705	305	1.2031
14. Illinois	10,974	4,364	.8392
15. Indiana	5,067	2,085	.9970
16. Iowa	2,748	1,117	1.0032
17. Kansas	2,303	920	1.0325
18. Kentucky	3,229	1,341	1.3233
19. Louisiana	3,732	1,670	1.3051
20. Maine	979	404	1.1923
21. Maryland	3,757	1,565	.9193
22. Massachusetts	5,437	2,118	.8989
23. Michigan	8,740	3,670	.9151
24. Minnesota	3,646	1,529	1.0224
25. Mississippi	2,342	1,081	1.6879
26. Missouri	4,627	1,801	1.0515
27. Montana	693	305	1.1294
28. Nebraska	1,437	591	1.0262
29. Nevada	453	190	.8558
30. New Hampshire	702	276	1.0499
31. New Jersey	7,078	2,716	.8565
32. New Mexico	1,015	496	1.2561
33. New York	18,113	6,888	.8419
34. North Carolina	5,135	2,158	1.3147
35. North Dakota	625	282	1.2347
36. Ohio	10,591	4,329	.9726
37. Oklahoma	2,518	980	1.2017
38. Oregon	2,008	787	1.0154
39. Pennsylvania	11,712	4,456	.9957
40. Rhode Island	913	350	.9653
41. South Carolina	2,692	1,187	1.4534
42. South Dakota	657	294	1.2230
43. Tennessee	3,976	1,591	1.3320
44. Texas	10,972	4,711	1.1617
45. Utah	1,034	488	1.1904
46. Vermont	422	172	1.1336
47. Virginia	4,597	1,928	1.1347
48. Washington	3,276	1,264	.9174
49. West Virginia	1,805	724	1.3618
50. Wisconsin	4,213	1,762	1.0025
51. Wyoming	315	137	1.0660
52. Guam	98	50	1.6879
53. Puerto Rico	2,729	1,420	1.6879
54. Virgin Islands	62	28	1.6879
55. American Samoa	31	17	1.6879

Question 3. When you submit the list of state allotments for 1969, will you please also compute and list the amount that would be allotted to each state on a per capita basis, and the amount that would be allotted to each state on the basis of the need for facilities for the mentally retarded?

HYPOTHETICAL ALLOCATIONS, 1969

	Construction (pt. C)		Initial staffing (pt. D)	
	Population only	Need only	Population only	Need only
Total	$12,000,000		$8,358,000	
1. Alabama	211,020	221,976	146,975	154,606
2. Alaska	16,392	20,448	11,417	14,242
3. Arizona	98,820	107,004	68,828	74,528
4. Arkansas	119,064	118,740	82,928	82,702
5. California	1,137,444	1,129,884	792,230	786,964
6. Colorado	121,200	121,644	84,416	84,725
7. Connecticut	175,104	166,740	121,960	116,134
8. Delaware	31,596	32,772	22,007	22,826
9. District of Columbia	47,880	45,672	33,348	31,811
10. Florida	364,536	339,852	253,899	236,707
11. Georgia	271,500	287,076	189,100	199,948
12. Hawaii	46,044	49,728	32,070	34,636
13. Idaho	41,724	44,220	29,061	30,799
14. Illinois	649,404	632,724	452,310	440,692
15. Indiana	299,856	302,292	208,850	210,546
16. Iowa	162,624,	161,952	113,268	112,800
17. Kansas	136,284	133,392	94,922	92,908
18. Kentucky	191,088	194,424	133,093	135,416
19. Louisiana	220,848	242,124	153,821	168,639
20. Maine	57,936	58,572	40,352	40,795
21. Maryland	222,324	226,908	154,849	158,041
22. Massachusetts	321,744	307,080	224,095	213,881
23. Michigan	517,212	532,104	360,238	370,629
24. Minnesota	215,760	221,688	150,277	154,406
25. Mississippi	138,588	156,732	96,527	109,164
26. Missouri	273,816	261,120	190,713	181,870
27. Montana	41,004	44,220	28,559	30,799
28. Nebraska	85,032	85,692	59,225	59,684
29. Nevada	26,808	27,552	18,672	19,190
30. New Hampshire	41,544	40,020	28,935	27,874
31. New Jersey	418,860	393,780	291,736	274,268
32. New Mexico	60,060	71,916	41,832	50,089
33. New York	1,071,876	998,676	746,562	695,578
34. North Carolina	303,876	312,876	211,650	217,918
35. North Dakota	36,984	40,884	25,759	28,476
36. Ohio	626,748	627,648	436,530	437,157
37. Oklahoma	149,004	142,092	103,781	98,967
38. Oregon	118,824	114,108	82,761	79,476
39. Pennsylvania	693,084	646,068	482,733	449,986
40. Rhode Island	54,024	50,748	37,628	35,346
41. South Carolina	159,300	172,104	110,952	119,870
42. South Dakota	38,880	42,624	27,080	29,688
43. Tennessee	235,284	230,676	163,875	160,666
44. Texas	649,296	683,040	452,235	475,737
45. Utah	61,200	70,752	42,626	49,279
46. Vermont	24,972	24,936	17,393	17,368
47. Virginia	272,040	279,540	189,476	194,700
48. Washington	193,860	183,264	135,023	127,643
49. West Virginia	106,812	104,964	74,395	73,107
50. Wisconsin	249,312	155,468	173,646	177,933
51. Wyoming	18,636	19,860	12,980	13,832
52. Guam	5,892	7,200	4,104	5,015
53. Puerto Rico	161,496	205,884	112,482	143,398
54. Virgin Islands	3,696	4,116	2,574	2,867
55. American Samoa	1,812	2,424	1,262	1,688

Question 4. Will you please provide us with tables comparable to those in questions 1–3 above, for the allotment of funds under Part D of title I of the Act?

(See replies to questions 1 to 3 above.)

Question 5. It is my understanding that the Division of Mental Retardation has also been administering a project grant program of assistance to state residential institutions for the retarded, to improve their programs and provide in-service training. These are the so-called HIP and HIST programs. (a) Will you please provide a brief explanation of each of these programs and its relationship to the programs carried out under Title I?

The Hospital Improvement Program and the University Affiliated Community Facilities Construction and Initial Staffing Programs

These are key programs in the overall Federal mental retardation effort. They reinforce each other, but are contiguous rather than overlapping.

The Hospital Improvement Program concentrates on improving services to the institutionalized mentally retarded, an area that has no other specific support through Federal programs. Support is provided for (1) the demonstration of improved methods of care, treatment and rehabilitation of the retarded in state institutions and (2) the inservice training of personnel employed in such institutions.

The population of most residential facilities is predominantly made up of severely and profoundly retarded (57%), who are often also multiple handicapped. There has been a trend away from services to the mildly retarded to a higher concentration on improved care and strengthened therapeutic programming for the severely and profoundly retarded. The Hospital Improvement Program, through concentration on specific services by better trained staff, is making life more meaningful for those who must stay within the institution by helping them attain their maximum potential for mobility and self-care. It also has done much to increase the potential for community placement of the mild and moderate residents of institutions.

The Community Construction and Staffing programs provide the keystone or cohesive elements of the community continuum of services through evaluation of individual needs and providing the retarded with the foundation of readiness which permits them to participate in education, rehabilitation and other generic programs. In addition, these programs are designed to permit communities to fill the gaps between the generic and other available specialized services locally available. This encourages the development of a basic system of services in each community so that most retarded individuals can remain in their home communities and progress from one service to another without losing the advantage gained in one program for lack of an appropriate succeeding or follow-up service.

The University Affiliated Facilities Program provides grants to assist in the construction of facilities affiliated with a university or college. These facilities provide programs of interdisciplinary training based on exemplary models of comprehensive services to the mentally retarded. The multidisciplinary training programs within a University Affiliated Facility, housing an extensive array of services for the retarded citizens of all ages, will provide trained manpower and demonstration of modernized service and coordination to improve and expand the community and institutional programs supported by HEW agencies.

(*b*) *How much money is allowed per institution for grants under each of these programs?*

The Mental Retardation Hospital Improvement Program (HIP) allows a maximum of $100,000 per institution each fiscal year; the Hospital Inservice Training program (HIST) allows a maximum of $25,000 per institution each fiscal year.

(*c*) *How much would you need to fully fund these programs—i.e., to permit maximum participation by eligible institutions?*

To permit maximum participation by currently eligible institutions at the program budget ceiling, an estimated $18,000,000 for the HIP program and $4,500,000 for the HIST program would be required to fully fund these programs.

(*d*) *Will you please provide a state-by-state table of your grant totals for each of these two programs in 1969? In the table, please list also the number of residents in the state institutions receiving awards, and the per resident awards for HIP and HIST grants in each state.*

HOSPITAL IMPROVEMENT PROGRAM (HIP) AND HOSPITAL INSERVICE TRAINING PROGRAM (HIST), 1969, STATE-BY-STATE BREAKDOWN

	HIP			HIST		
	Fiscal year 1969 awards	Number of residents	Per resident award	Fiscal year 1969 awards	Number of residents	Per resident award
REGION I						
Connecticut, total	$299,988	4,005	$75	$49,974	3,765	$13
Seaside	100,000	240	417			
Southbury	99,988	2,018	50	24,974	2,018	12
Mansfield	100,000	1,747	57	25,000	1,747	14
Maine, total: Pineland				24,632	1,148	21
Massachusetts, total	161,484	7,443	22	65,562	3,249	20
Belchertown	7,276	1,289	6	23,068	1,289	18
Dover	95,186	1,885	50	18,051	1,885	10
Fernald	8,715	2,585	3			
Hathorne				24,443	75	326
Wrentham	50,307	1,684	30			
New Hampshire, total: Laconia	100,000	1,020	98	25,000	1,020	25
Rhode Island, total: Ladd				25,000	918	27
Vermont, total: Brandon	88,806	754	118	22,572	754	3 0
REGION II						
Delaware, total: Hospital for MR	65,965	618	107			
New Jersey, total	380,689	5,816	65	147,113	7,072	21
Johnstone	68,968	492		23,124	492	47
New Lisbon				25,000	1,256	20
North Jersey	94,571	1,091	87	24,492	1,091	22
Vineland	74,125	2,020	37	24,776	2,020	12
Woodbine	61,714	1,213	51	25,000	1,213	21
Woodbridge	81,311	1,000	81	24,721	1,000	25
New York, total	421,510	15,729	27	47,342	8,471	6
Craig	83,127	1,877	44	23,299	1,877	12
Newark	92,531	2,563	36	13,472	2,563	5
Rome	62,518	4,031	16	10,571	4,031	3
West Seneca	99,992	1,669	60			
Willowbrook	83,342	5,589	15			
Pennsylvania, total	58,724	851	69	58,363	2,964	20
Cresson				20,150	606	33
Ebensburg				24,500	1,040	24
Laurelton				7,728	798	10
Western				5,985	520	12
White Haven	58,728	851	69			
REGION III						
District of Columbia, total: District of Columbia Training	91,941	1,310	70	26,012	1,310	20
Kentucky, total: Outwood	31,261	474	66	22,127	685	32
Maryland, total				41,357	3,150	13
Henryton				20,017	403	50
Rosewood				21,340	2,747	8
North Carolina, total	159,472	2,174	73	50,000	2,174	23
Murdoch	59,472	1,600	37	25,000	1,600	16
Western Carolina	100,000	574	174	25,000	574	44
Virginia, total	86,777	3,618	24	40,565	3,978	10
Petersburg				25,000	360	69
Lynchburg	86,777	3,618	24	15,565	3,618	4
West Virginia, total: C. Anderson	45,019	556	81			
REGION IV						
Alabama total: Partlow	81,797	2,290	36			
Florida total	96,654	361	268	60,928	2,978	20
Marianna				23,500	970	22
Miami	96,654	361	268			
Orlando Hospital				15,533	1,000	16

HOSPITAL IMPROVEMENT PROGRAM (HIP) AND HOSPITAL INSERVICE TRAINING PROGRAM (HIST), 1969, STATE-BY-STATE BREAKDOWN—Continued

	HIP			HIST		
	Fiscal year 1969 awards	Number of residents	Per resident award	Fiscal year 1969 awards	Number of residents	Per resident award
Georgia total: Gracewood	99,659	1,922	52	25,000	1,922	13
South Carolina total	279,205	3,541	79	48,487	948	51
Habil. Ctr	90,061	500	180	23,487	500	47
Pineland	100,000	448	223	25,000	448	56
Whitten Village	100,000	2,593	34			
Tennessee total	155,613	2,464	63	45,771	1,541	30
Arlington				20,771	65	320
Clover Btm	58,326	1,476	40	25,000	1,476	17
Greene Valley	97,287	988	98			
REGION V						
Illinois, total	332,741	5,286	63	52,053	5,012	10
A. L. Bowen				24,999	240	104
Dixon	99,896	4,072	25	22,170	4,072	5
Ill. Ped. Inst	53,226	264	202			
W. G. Murray	113,699	700	162	4,884	700	7
W. W. Fox	65,920	250	264			
Indiana, total	115,672	3,307	35	19,589	2,058	10
Muscatatuck				19,589	2,058	10
Fort Wayne	85,516	2,507	34			
New Castle	30,156	800	38			
Michigan, total	376,097	5,957	63	79,489	8,063	10
Caro	98,273	1,932	51			
Coldwater				25,000	3,023	8
Fort Custer	99,687	1,334	75			
Howell				9,367	374	25
Lapeer				25,000	3,431	7
Mount Pleasant	100,000	1,456	69			
Plymouth	78,137	1,235	63	20,131	1,235	16
Ohio, total: Columbus	85,373	2,162	39	25,000	2,162	12
Wisconsin, total	251,939	4,086	62	75,000	4,086	18
Central Wisconsin	95,400	1,268	75	25,000	1,268	20
North Wisconsin	56,539	1,528	37	25,000	1,528	16
South Wisconsin	100,000	1,290	78	25,000	1,290	19
REGION VI						
Iowa, total: Glenwood	51,503	1,260	41	24,010	1,260	19
Kansas total	205,672	2,217	93	32,224	1,549	21
Kansas Neuro. I	41,312	403	103	15,318	403	38
Parsons	99,400	668	149			
Winfield	64,960	1,146	57	16,906	1,146	15
Minnesota, total	293,946	5,470	54	20,960	2,478	8
Brainard	100,000	1,406	71			
Cambridge	104,401	1,586	66			
Fairbault	89,545	2,478	36	20,960	2,478	8
Missouri, total	163,544	2,669	61	24,640	840	29
Marshall	91,613	1,829	50			
St. Louis	71,931	840	86	24,640	840	29
North Dakota, total: Grafton				25,000	1,396	18
South Dakota, total: Redfield	98,068	1,150	85			
REGION VII						
Arkansas total: Conway Childrens Colony	91,205	768	119	25,000	768	33
Louisiana total	100,000	1,902	53	73,598	2,302	32
Belle Chase				20,651	208	99
Pinecrest	100,000	1,902	53	25,000	1,902	13
Ruston				27,947	192	146

HOSPITAL IMPROVEMENT PROGRAM (HIP) AND HOSPITAL INSERVICE TRAINING PROGRAM (HIST), 1969, STATE-BY-STATE BREAKDOWN—Continued

	HIP			HIST		
	Fiscal year 1969 awards	Number of residents	Per resident award	Fiscal year 1959 awards	Number of residents	Per resident award
New Mexico total: Los Lunas				18,030	536	34
Oklahoma total	74,553	985	76	47,026	1,633	29
Enid	74,553	985	76	25,000	985	25
Hissom				22,026	648	34
Texas total	665,964	11,930	56	137,939	9,223	15
Abilene	96,700	2,307	42	25,000	2,307	11
Austin	89,425	2,418	37	31,223	2,418	9
Denton	84,949	1,700	50	22,389	1,700	13
Lufkin	100,000	697	143	21,568	697	31
Mexia	97,291	2,727	36			
Richmond	97,599	260	375	24,059	260	93
Travis	100,000	1,841	54	23,700	1,841	13
REGION VIII						
Colorado, total	152,937	1,910	80	49,655	1,910	26
Grand Junction	94,962	846	112	24,655	846	29
W.T. Ridge	57,975	1,064	54	25,000	1,064	23
Idaho, total: Station Hospital, Nampa	100,000	798	125	25,000	798	31
Montana, total: Boulder River	69,809	928	75	25,000	928	27
Utah, total: STS Am. Fk	90,216	1,063	85	24,450	1,063	23
Wyoming, total: STS Lander	95,765	721	133	25,000	721	35
REGION IX						
Arizona, total: Child. Col., Coolidge	97,132	1,040	93	24,499	1,040	24
California, total	291,304	8,696	33	48,635	6,259	8
Pacific	98,593	2,895	34	25,000	2,859	9
Porterville	98,238	2,437	40			
Sonoma	94,473	3,400	28	23,635	3,400	7
Hawaii, total: Waimano	96,046	835	115	24,570	835	29
Nevada, total: S.H. Reno				10,234	174	59
Oregon, total	100,000	2,477	40	49,347	3,005	16
Columbia Pk				24,347	528	46
Fairview	100,000	2,477	40	25,000	2,477	10
Washington, total	385,918	4,228	91	70,221	2,508	28
Firerest	100,000	950	105	25,000	950	26
Lakeland	90,076	1,308	69	20,227	1,308	15
Ranier	100,000	1,720	58			
Yakima Valley	95,842	250	383	24,994	250	100

Question 6. During the recent hearings, you pointed out that the mentally retarded benefit from a number of different programs in the Department, such as vocational rehabilitation, education of the handicapped, medicaid, income maintenance, and so on.

It is my understanding that the mentally ill also benefit from all or most of these programs. Will you please provide us with data for fiscal 1969, and the budget estimates for 1970 on all expenditures for research, training prevention, treatment, instruction, income maintenance, etc., for mental disorders other than mental retardation under programs administered by HSMHA, OE, SRS, and SSA? Please provide this material as far as possible by line items comparable to those included in the table at the end of your submission on mental retardation, referred to on page 9 of the transcript of your testimony. If possible, please prepare a new table comparing the new data with the data on mental retardation.

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

SOCIAL AND REHABILITATION SERVICE—OBLIGATIONS FOR MENTAL ILLNESS PROGRAMS BY ACTIVITY DESIGNATION, FISCAL YEARS 1969-70

	1969 actual	1970 estimate
Services	$257,877,930	$344,559,000
Training and personnel	410,738	327,735
Research	881,338	1,051,000
Construction and support services for rehabilitation facilities	1,070,000	865,000
Planning		
Income maintenance	56,000,000	65,000,000
Other		
Total	316,240,006	411,802,735

OFFICE OF EDUCATION—OBLIGATIONS INCURRED IN THE AREA OF "MENTAL HEALTH" (EXCLUDING "MENTAL RETARDATION") IN FISCAL YEARS 1969-70

	1969 actual	1970 estimate
Education for the handicapped:		
State grant programs (ESEA VI-A): Emotionally disturbed children	$2,530,000	$2,530,000
Teacher education (Public Law 85-926): Emotionally disturbed children	3,787,664	3,787,664
Research and demonstration (Public Law 88-164):		
Development of behavior dimensions for emotionally disturbed children, Vanderbilt University, Nashville, Tenn	68,002	
Identification and treatment of social emotional problems, University of Oregon, Eugene, Oreg	107,698	101,123
Education of behaviorally disordered children in the public school setting, Temple University, Philadelphia, Pa	119,138	
An investigation into the use of indigenous groupings as the reinforcement agent in teaching maladjusted boys to read, Yeshiva University, New York, N.Y		19,192
Crisis intervention: Secondary schools, University of Minnesota, Minneapolis, Minn	50,262	
Evaluation of a program to train teachers to manage social and emotional problems, American Institute for Research, Pittsburgh, Pa	111,618	
Evaluation of a program for reeducating disturbed children: A followup comparison with untreated children, George Peabody College for Teachers, Nashville, Tenn	72,676	65,221
The application of functional analysis of behavior by teachers in a natural school setting, University of Washington, Seattle, Wash	118,592	
Subtotal	6,965,650	6,412,200
Research and training: General education research and training (Cooperative Research Act):		
Postdoctoral fellowship program in educational research as related to community mental health, University of Pittsburgh, Pittsburgh, Pa	21,000	
The effect of assessement and personalized programing on subsequent intellectual development of prekindergarten and kindergarten, University City School District, Mo	30,749	12,133
Subtotal	51,749	12,133
Total	7,017,399	6,424,333

Note: Figures for education professions development are not available.

SOCIAL SECURITY ADMINISTRATION—EXPENDITURES FOR MENTAL HEALTH

	1969	1970
Disability benefit payments	$22,670,000	$24,970,000
Health insurance benefit payments:		
Part A	77,000,000	90,000,000
Part B	4,000,000	5,000,000
Total	81,000,000	95,000,000
Total, Social Security Administration	103,670,000	119,970,000

HEALTH SERVICES AND MENTAL HEALTH ADMINISTRATION EXPENDITURES FOR MENTAL HEALTH

[In thousands]

	1969				
	Comprehensive health	Indian health	Mental health	St. Elizabeths Hospital	Total
Formula grants to States	$9,917				$9,917
Research			$99,824	$526	100,350
Training and education			85,397	536	85,933
Construction of community mental health centers			28,290		28,290
Organization and delivery of health services			50,168		50,168
Clinical and community services		$1,290	13,020	10,501	24,811
Prevention and control			8,782		8,782
Total, expenditures for mental health by the Health Services and Mental Health Administration	9,917	1,290	285,481	11,563	308,251
	1970				
Formula grants to States	$13,500				$13,500
Research			$111,732	$351	112,083
Training and education			101,783	664	102,447
Construction of community mental health centers			36,100		36,100
Organization and delivery of health services			56,070		56,070
Clinical and community services		$1,423	14,500	11,589	27,512
Prevention and control			9,607		9,607
Total, expenditures for mental health by the Health Services and Mental Health Administration	13,500	1,423	329,792	12,604	357,319

Question 7. What criteria are used by the Administration to assess the relative needs of the mentally retarded as compared with the mentally ill.

No single set of criteria are or should be employed to assess the relative needs of the mentally retarded and the mentally ill. There are, in short, no trade-offs made directly between programs in these two areas. Rather, needs are assessed in the much broader context of the overall health, rehabilitation, and social services programs of the Department.

Question 8. Will you please provide the latest available data on a state-by-state basis on resident populations in state and private mental hospitals, and state and private residential facilities for the mentally retarded?

STATE-BY-STATE BASIS ON RESIDENT POPULATIONS IN STATE AND PRIVATE MENTAL HOSPITALS, AND STATE AND PRIVATE RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED

	Resident patients			
	Mental hospitals		Institutions for the mentally retarded	
	State and county 1968	Private 1967	Public 1968	Private [1] 1968
Total, United States	400,681	13,764	192,520	[2] 6,243
1. Alabama	7,699	(3)	2,343	(4)
2. Alaska	164	(3)	96	(3)
3. Arizona	1,128	83	988	[2] 176
4. Arkansas	1,667	(3)	857	(3)
5. California	18,938	1,116	13,355	[2] 436
6. Colorado	1,641	211	2,424	70
7. Connecticut	6,100	607	4,154	[2] 12
8. Delaware	1,396	(3)	587	(4)
9. District of Columbia	5,477	63	1,308	
10. Florida	9,603	215	5,156	[2] 222
11. Georgia	10,809	202	1,700	(4)
12. Hawaii	595	(3)	801	(3)
13. Idaho	633	(3)	700	(3)
14. Illinois	21,561	683	9,135	[2] 1,185
15. Indiana	9,940	42	3,837	(3)
16. Iowa	1,449	(3)	1,684	0
17. Kansas	2,101	193	1,967	(3)
18. Kentucky	3,901	262	1,088	(4)
19. Louisiana	5,135	96	2,775	[2] 164
20. Maine	2,796	15	910	(4)
21. Maryland	7,941	779	3,178	(3)
22. Massachusetts	15,095	1,410	7,951	[2] 274
23. Michigan	15,294	891	12,942	[2] 152
24. Minnesota	4,244	(3)	5,215	[2] 108
25. Mississippi	5,123	615	1,353	(3)
26. Missouri	7,488	251	2,628	[2] 279
27. Montana	1,376	(3)	944	(3)
28. Nebraska	2,059	37	2,205	(4)
29. Nevada	451	(3)		(4)
30. New Hampshire	2,158	(3)	1,053	22
31. New Jersey	16,762	283	6,687	[2] 45
32. New Mexico	646	71	760	(3)
33. New York	79,008	1,316	27,632	[2] 320
34. North Carolina	8,259	161	4,659	[2] 58
35. North Dakota	1,208	(3)	1,348	(3)
36. Ohio	20,866	366	9,599	[2] 141
37. Oklahoma	3,832	46	1,996	[2] 24
38. Oregon	2,219	36	2,957	83
39. Pennsylvania	30,793	2,080	11,591	[2] 1,396
40. Rhode Island	1,947	123	857	(4)
41. South Carolina	5,896	23	3,305	(3)
42. South Dakota	1,342	(3)	1,236	(3)
43. Tennessee	6,983	37	2,266	(4)
44. Texas	14,235	478	10,104	[2] 239
45. Utah	542	(3)	1,142	(4)
46. Vermont	1,079	338	667	(3)
47. Virginia	11,371	259	3,587	[2] 119
48. Washington	2,930	57	4,043	(4)
49. West Virginia	4,594	22	443	(3)
50. Wisconsin	11,698	297	3,658	[2] 718
51. Wyoming	509	(3)	649	(3)

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[1] Reporting from 74 of 188 institutions.
[2] Partial reporting.
[3] No facilities of this type in operation for year reported.
[4] Not reported.

Senator **Kennedy**. Our next witnesses will be a panel to discuss the bill with specific reference to title II, which deals with university-affiliated facilities for the mentally retarded.

I am pleased to welcome you, Dr. Gibson, and your distinguished associates.

Dr. Gibson is well known to the committee as a pioneer in the field of interdisciplinary training for service to the retarded.

Dr. Moser is well known to me for his connection with the Walter E. Fernald State School in Waverly, Mass., which is unique in its position as the only university-affiliated facility operated in conjunction with a State school for the retarded.

Dr. Cohen's institution in Michigan is pioneering in new approaches to social and psychological training of the retarded.

Dr. Cochran's program in Texas is one of the newest facilities in the Nation and represents the variety of facilities whose growth has been encouraged by the existing programs.

I welcome each of you gentlemen, and we look forward to your testimony.

STATEMENTS OF WILLIAM M. GIBSON, M.D., DIRECTOR, UNIVERSITY-AFFILIATED MENTAL RETARDATION TRAINING PROGRAM, OHIO STATE UNIVERSITY, COLUMBUS, OHIO, AND PRESIDENT, ASSOCIATION OF DIRECTORS AND ADMINISTRATORS OF UNIVERSITY-AFFILIATED CENTERS; HUGO MOSER, M.D., DIRECTOR OF RESEARCH AND TRAINING, WALTER E. FERNALD STATE SCHOOL, WAVERLY, MASS.; JULIUS COHEN, PH. D., ASSOCIATE DIRECTOR, INSTITUTE FOR THE STUDY OF MENTAL RETARDATION, UNIVERSITY OF MICHIGAN, ANN ARBOR, MICH.; AND WINSTON COCHRAN, M.D., DIRECTOR, CHILD DEVELOPMENT CLINIC, TEXAS CHILDREN'S HOSPITAL, HOUSTON, TEX.

Dr. GIBSON. Thank you, Senator Kennedy and Senator Dominick. I am the director of the university-affiliated mental retardation training program at Ohio State University and also to be the president of the Association of Directors and Administrators of the University-Affiliated Centers.

Accompanying me this morning are Dr. Hugo Moser, who presents the point of view of a university-affiliated facility located in an area where it has an integral association with a long-established institution; Dr. Julius Cohen, who represents a program which has reached maturity recently and shows the kinds of interrelationship that can be made between university departments and States and communities; Dr. Winston Cochran, from the Texas Children's Hospital in the Houston area which represents the problem faced by a number of large geographic areas that are currently not represented in the university-affiliated centers program.

First, I would like to express our appreciation for the opportunity to appear before your distinguished subcommittee in order that we may express our full support of S. 2846, the Developmental Disabilities Services and Facilities Construction Act of 1969.

Our association is composed of the directors and administrators of the 19 approved and funded universities, and the 10 universities whose programs have been submitted and are awaiting recommendations at this present time.

In addition, there are approximately 30 other major universities in this country that are in various stages of planning up to the submission of completed proposals that represent the interface between the community and zonal needs for the management and concern of people who have retarded children and children with related disabilities and the need to staff the programs with appropriately trained professional and other types of interested trained people.

First, the university-affiliated centers have an integral part in their development of community and State plans.

This type of relationship is important to the universities. It is manifested as an outgrowth in certain areas of State activities in planning for the needs of the retarded and handicapped and perhaps helps identify why some of the people who are here this morning are people who have already come to the acquaintance of those of us who are concerned with the university aspect of this overall problem.

This is not a program that is outside the main theme of the need for services for the developmentally disabled.

Senator DOMINICK. Dr. Gibson, you say 19 funded universities. Funded by whom?

Dr. GIBSON. Construction of these university-affiliated facilities is funded by the Division of Mental Retardation, a part of the Social and Rehabilitation Services Administration. Cincinnati, as you may well be aware, has been approved but has not had any release of construction funds for their particular facility.

Senator DOMINICK. The funded universities you are talking about are matching university funds, local funds and Federal funds?

Dr. GIBSON. That is right.

Senator DOMINICK. Thank you.

Dr. GIBSON. The university-affiliated center is probably the primary activity in universities in this Nation in the attempt to have disciplines from various departments in colleges or in schools such as social work relate to one another in a method of planning that will allow the university to use and move out into the community as part of the teaching experience for the students who come to a university.

Those of you who heard Prince Philip this morning on the "Today Show" heard him indicate that universities have some Victorian tendencies. We are willing to concede this and we think that the opportunity represented by this program for universities to cross their walls and to become more visible may be an important turning point.

Again, the prevention aspect that has been mentioned by the administration is a primary concern to the universities as well as the training of people to meet the needs of the families of the retarded. Evaluation of a program which is relatively new in time is another critical aspect that we would like the committee to consider.

From the university point of view we are concerned that we continue to have the opportunity to relate to geographic areas, and to the needs of people, and that in the training of students we accentuate the opportunity for these individuals to go out into the community and be able to occupy roles in community or regional facilities without long periods of orientation and costly further training.

A program of this nature does not occur overnight, however. The buildup of programs within a university and within a community takes a number of years. At capacity the presently funded programs will be able to offer the community roughly 200 individuals in various professional areas who will be highly trained in a broad area of concern with the mentally retarded.

Roughly three times that number, or 600 from each facility, will be exposed at least for one quarter of the year or one semester to specific course work or academic interest in the problems of the retarded and developmentally handicapped.

Again through these facilities and their location within universities and communities, roughly 1,000 to 3,000 students from areas such as primary education, home economics, social sciences, and similar disciplines will have contact with what our society sees as some of the primary concerns in this area.

The universities have a strong commitment to this. When a university makes or develops an agreement to undertake such a program they commit themselves to a 20-year period of utilizing this facility as well as utilizing the resources of their faculty and the resources that they can mobilize in support of these particular programs.

So this adds something to a university's development of interdisciplinary programs.

What do we mean by interdisciplinary? This is a point of confusion in our language. I was interested in the previous witnesses who expressed concern about "developmental disabilities" as a defined phrase.

The majority of people working with the retarded and handicapped use the term "development" as an interruption in the sequence of orderly growth and capacity, not development in the uterus, for example, that might limit the growth and development of one arm or leg.

So that when we talk to the different disciplines we find that the majority of the people concerned are developmentally oriented and use measures of development as a means of identifying the retarded and disabled.

How do we then bring these disciplines into communication with one another and into an opportunity to train students who can interact with one another?

This we think is the primary role of these particular programs. The social worker, the sociologist, the medical student, the lawyer, the various people who will be given an opportunity through these programs to extend their learning, will leave with the intricate knowledge of how to relate and communicate with people of other disciplines, rather than fostering a cloistered approach to their own disciplinary rights.

The need to identify with other disciplines might be brought to light in the sequence of events commonly seen throughout the Nation where a family is seen by a psychologist who writes a report, seen by a social worker who writes a report, seen by a physician, maybe a pediatrician or phychiatrist who writes a report, and we find 60 to 70 percent overlap in the report and we find discussion concerning the family taking place at a time when their physical presence has long since been lost.

The university-affiliated centers feel the need to develop a more active and more integral approach to the needs of the people so that the disciplines confer with one another on an equal status, equal contact basis, and that arising out of a rapid management orientation to the problems of a family within this community or within this area.

These programs will need to provide exemplary services if we are going to offer the spectrum of training that we feel is critical.

We agree with the administration people on the relationship of the problem to the lower socioeconomic spectrum of our society and also to certain social, cultural elements within our society.

We feel that the opportunity for a university to take students into the areas of greatest concern and to work with the development of community-based facilities will be one of the strong points that university-affiliated centers can provide. These services like other medical and educational and social services are costly in operation because the numbers of families seen in relation to the training of individuals is costly.

We cannot use criteria that are service-based and with the number of people run through per hour as a means of justifying this type of program.

However, the spectrum of training that this legislation has opened to universities is something that is certainly a strong supportive element.

For the first time we have areas such as sociology, we have law students, we have people such as nutritionists in the social sciences, people in physical and occupational therapy working toward a solution of a family's problem.

If the family sees their prime problem as a speech problem, then they have the opportunity to relate to such a student and to such a faculty person rather than I am afraid the approach we frequently take that if you have 28 hours of assessment then we can tell you to whom you can relate.

The construction requirement in the eyes of the people we represent—the universities throughout the Nation—is a very important part of the visibility that will be required and the centralization for ongoing education and State support that we will need if these programs are going to be successful.

We agree with Senator Dominick that the pattern of State involvement and State support as well as community moneys will be the operating solution of these programs as well as the community-based facilities.

To achieve this, however, there must be a central focus around which this operates. The rather modest amount of $20 million per year would provide the opportunity for four to five new programs in universities to be developed each year.

As you know from the number of proposals now awaiting consideration there is certainly a backlog.

This legislation does introduce something which is different than the previous legislation in its provision for basic operational support. This is crucial if universities are going to be successful in inaugurating this type of program.

There are administrative costs related to the development of a program of this stature, the need to bring in support of staff other than the trainers, the faculty and the trainees, the student as well as persons who are not covered in the present training grant areas through which the programs receive their operative support.

Finally, the outgrowth of the support that we see of university-affiliated centers through this legislation is perhaps the partial solution of the manpower shortage and the need to mobilize appropriate manpower that may relate to the original President's Committee on Mental Retardation which demonstrated that the parents of this Nation are anxious to have the needs of the retarded and developmentally disabled met within their communities and in relation to the remainder of the family.

Thank you.

(The prepared statement of Dr. Gibson follows:)

PREPARED STATEMENT OF WILLIAM M. GIBSON, M.D., DIRECTOR OF UNIVERSITY-AFFILIATED MENTAL RETARDATION TRAINING PROGRAM, OHIO STATE UNIVERSITY

Mr. Chairman, Members of the Subcommittee, I am William M. Gibson, M.D., Director of the University-Affiliated Mental Retardation Training Program at Ohio State University. I am also the president of the Association of Directors and Administrators of University-Affiliated Centers. Accompanying me this morning are:

Hugo Moser, M.D., Director of Research and Training at Walter E. Fernald State School in Waverly, Mass.

Julius Cohen, Ph. D., Associate Director of Institute for the Study of Mental Retardation, University of Michigan in Ann Arbor.

Winston Cochran, M.D., Director of Child Development Clinic, Texas Children's Hospital, Houston.

On behalf of the Association of Directors and Administrators of University-Affiliated Centers, may I express our appreciation for the opportunity to appear before your distinguished sub-committee in order that we may express our full support of S. 2846, the Developmental Disabilities Services and Facilities Construction Act of 1969.

Our Association is composed of the Directors and Administrators of the nineteen approved and funded universities, ten universities in the final stages of planning and program development and approximately thirty other universities in the early stages of planning. A full list of our membership is appended.

The plight of the developmentally disabled has been amply documented by the President's Committee on Mental Retardation. The only questions remaining are the degree of involvement by Federal, state and local interests, and the required implementation for producing the needed trained personnel to deal with the problems of those who are afflicted.

As a reflection of public concern, enactment of the Mental Retardation Facilities Construction Act presumed the need for hundreds of community mental retardation centers in order to bring treatment near the patient, and for thousands of trained professional personnel to provide the treatment in the community centers. Breakdowns in the construction sequence have occurred which, if permitted to continue, will further jeopardize the impetus created by Public Law 88–164. The "seeding effect" has been too small and too sporadic in a field with a rich potential harvest of employable humans.

Interdisciplinary training programs designed to produce large numbers of newly trained professional personnel require an extensive period of time and a large outlay of initial funding. An impressive number of universities are committed in writing to undertake these training endeavors. Imaginative, wide-ranging programs of this type dictate significant sums being spent for construction and staffing over the twenty years to which Congress has committed them for training. The cost of staffing is such that, although state and local support is vigorously sought, it is clear that the Federal Government must be prepared to carry the major share of the initial funding load if the mandate of these centers is to be achieved. We feel that S. 2846 constitutes such an effort in the amendments to Title II.

At present, 242 community facilities have been approved under Part C, Title I of Public Law 88–164. This is a laudable achievement for the architects of the community care concept and we again recommend the passage of S. 2846 because community centers are given increased funding authorization in the section amending Title I.

We submit that the passage of the Mental Retardation Facilities Construction Act constituted a national plan for mental retardation. Stated briefly, the objectives of that plan were fundamentally three in number.

1. Improving the services provided to the mentally retarded and handicapped.

2. Improving the tempo and quality of professional personnel required to serve the mentally retarded and handicapped.

3. Broadening of research focused upon the prevention of mental retardation and handicapping.

There is no conflict in the three fundamental objectives. One leads logically to the next, and is dependent upon the one before. Advancing the cause of service to the developmentally disabled requires a network of community or zonal centers. Providing manpower for the community or zonal centers requires a network of university training centers. University training has, as a natural concommitant, research projects into the ameliorative and preventive aspects of the developmentally disabled.

SUMMARY

Delays in funding have already shaken the determination of many of the several dozen other universities which had previously made overtures to initiate University-Affiliated Centers. Further interruptions will materially jeopardize the intent of the original legislation.

The need for passage of S. 2846 is urgent. It is an excellent bill designed to bolster a sequence of endeavors which have proven the validity and wisdom of the legislation to be amended.

The Directors and Administrators of University-Affiliated Centers wholeheartedly endorse S. 2846 and thank the sub-committee for this opportunity to voice our support.

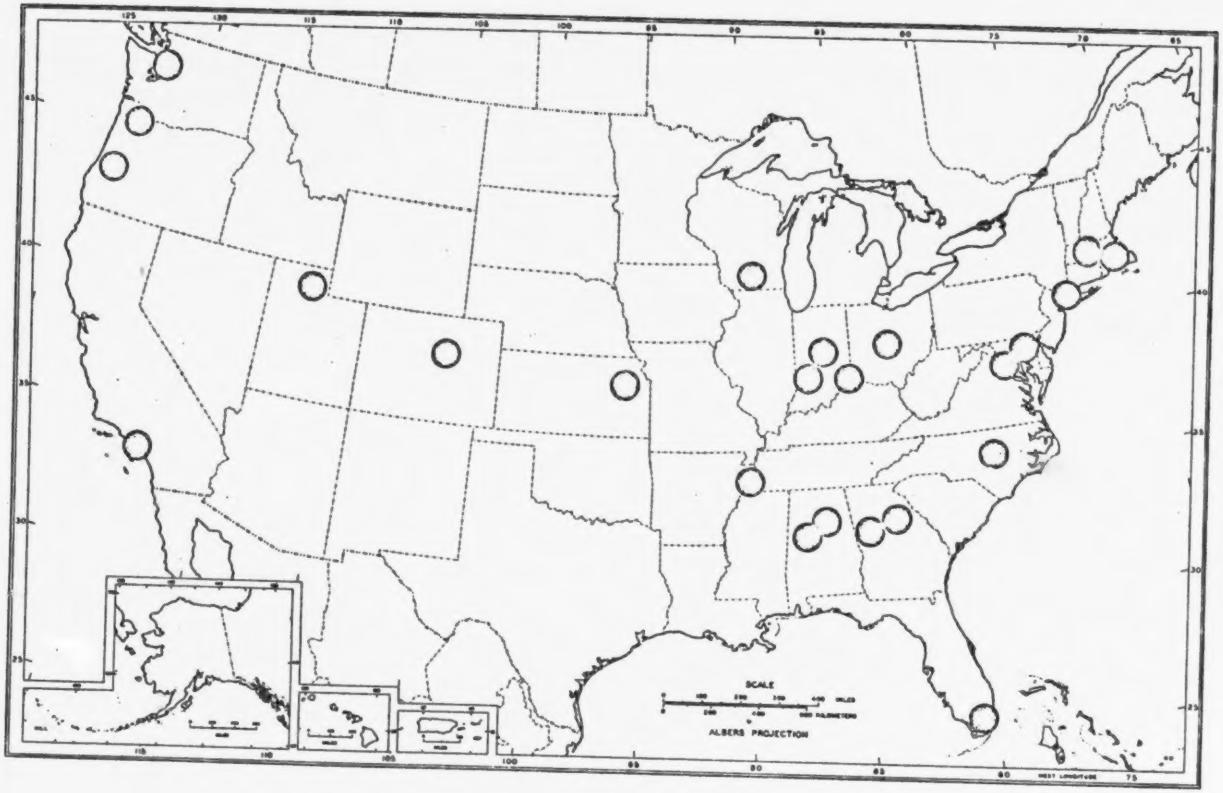
Program Directors
(or Contacts)

University-Affiliated Centers

University	Name	City	State
Alabama	Andrew E. Lorincz, M.D.	Birmingham	Alabama
Alabama	Alfred A. Baumeister	Tuscaloosa	Alabama
Albert Einstein	Larry Taft, M.D.	New York	New York
Arizona	David Wayne Smith, Ed.D.	Tucson	Arizona
Arkansas	Roger B. Bost, M.D.	Little Rock	Arkansas
Baylor	Winston, C. Cochran, M.D.	Houston	Texas
Boston	Allen C. Crocker, M.D.	Boston	Massachusetts
Boston	Hugo W. Moser, M.D.	Waverley	Massachusetts
Brandeis	Nathan E. Sklar	Warwick	Rhode Island
Brown	Allen R. Menefee	Providence	Rhode Island
California	Thomas L. Nelson, M.D.	Irvine	California
California	Irving Phillips, M.D.	San Francisco	California
California	George Tarjan, M.D.	Los Angeles	California
Cincinnati	Jack H. Rubinstein, M.D.	Cincinnati	Ohio
Colorado	Harold P. Martin, M.D.	Denver	Colorado
Connecticut	John Crawley, Ph.D.	Storrs	Connecticut
Duke	M.R. Project Director	Durham	North Carolina
Georgetown	Robert J. Clayton, M.D.	Washington	D.C.
Georgia	Andrew L. Shotick	Athens	Georgia
Georgia	James D. Clements, M.D.	Atlanta	Georgia
Idaho	Donald F. Kline, Ph.D.	Pocatello	Idaho
Indiana	Milton Wisland, Ph.D.	Bloomington	Indiana
Indiana	Morris Green, M.D.	Indianapolis	Indiana
Inst. of Logopedics	Charles W. Wurth	Wichita	Kansas
Iowa	R. R. Rembolt, M.D.	Iowa City	Iowa
Johns Hopkins	Frederick Richardson, M.D.	Baltimore	Maryland
Kansas	Richard L. Schiefelbusch, Ph.D.	Lawrence	Kansas
Kentucky	Vernon L. James, M.D.	Lexington	Kentucky
Louisiana State	Merle F. Warren, Ed.D.	Baton Rouge	Louisiana
Louisiana State	George R. Meneely, M.D.	New Orleans	Louisiana
Louisville	Bernard Weiskopf, M.D.	Louisville	Kentucky
Marquette	J. C. Peterson, M.D.	Milwaukee	Wisconsin
Miami	Samuel T. Giammona, M.D.	Miami	Florida
Michigan	Julius S. Cohen, Ed.D.	Ann Arbor	Michigan
Minnesota	John A. Anderson, M.D.	Minneapolis	Minnesota
Mississippi	Jerry H. Robbins	University	Mississippi
Missouri	Rodman P. Kabrick, Ph.D.	Columbia	Missouri
Nebraska	Paul Pearson, M.D.	Omaha	Nebraska
Newark State College	Edward LaCrosse, Ed.D.	Union	New Jersey
New York	Margaret Giannini, M.D.	New York	New York
North Carolina	Harrie R. Chamberlin, M.D.	Chapel Hill	North Carolina

Program Directors

University	Name	City	State
Ohio State	William M. Gibson, M.D.	Columbus	Ohio
Oklahoma	Logan Wright, Ph.D.	Oklahoma City	Oklahoma
Oregon	Robert H. Mattson, Ed.D.	Eugene	Oregon
Oregon	Leroy O. Carlson, M.D.	Portland	Oregon
Pennsylvania State	William R. Carriker, Ed.D.	University Park	Pennsylvan
Purdue	Earl J. Heath, Ed.D.	Lafayette	Indiana
Rutgers	Larry B. Silver, M.D.	New Brunswick	New Jersey
Southern California	Richard Koch, M.D.	Los Angeles	California
Southern Florida	Calvin M. Pinkard, Jr., Ph.D.	Tampa	Florida
St. Louis	Allan Barclay, Ph.D.	St. Louis	Missouri
Tennessee	Robert G. Jordan, M.D.	Memphis	Tennessee
Texas	Charles W. Daschmer, Jr. M.D.	Galveston	Texas
Texas Women's	Ted W. Booker, Ph.D.	Denton	Texas
Tufts	Marshall B. Kreidberg, M.D.	Boston	Massachus
Tulane	Robert C. Heath, M.D.	New Orleans	Louisiana
Utah State	Oral L. Ballum, Ph.D.	Logan	Utah
Vanderbilt	Donald J. Stedman, Ph.D.	Nashville	Tennessee
Virginia	Jack R. Gallagher	Charlottesville	Virginia
Washington	Robert Deisher, M.D.	Seattle	Washingto
Western Reserve	Jane Kessler, Ph.D.	Cleveland	Ohio
Wisconsin	Rick Heber, Ph.D.	Madison	Wisconsin
Yale	Albert J. Solnit, M.D.	New Haven	Connecticu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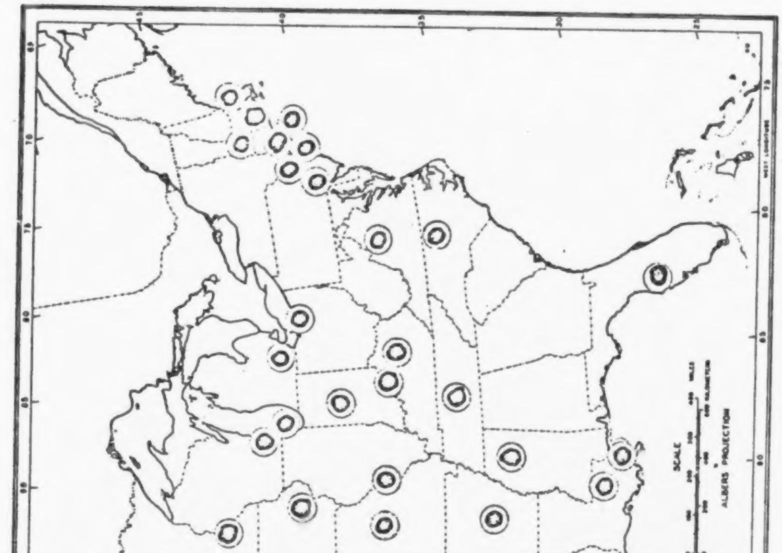
LOCATIONS OF APPROVED AND FUNDED PROGRAMS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LOCATIONS OF DEVELOPING PROGRAMS

Senator **Kennedy**. Dr. Gibson, would you tell us why you consider the university-affiliated concept to be the most valuable approach to the problem of the retarded and other developmental disabilities?

Dr. **Gibson**. I would like Dr. Hugo Moser to comment on that.

Dr. **Moser**. Our University-Affiliated Center is the Eunice Kennedy Shriver Center. It is located at the Walter Fernald State School, which is the oldest institution for the retarded in the Western Hemisphere and is the largest in Massachusetts.

To answer your question very succinctly, the problem has always been that most of the retarded are in the institution or in the community where the universities are located. To bring the two together is what has been to us the prime virtue of the university-affiliated facilities.

In our center the matching funds were provided by the State of Massachusetts and not the university. Our center has associated with it primarily the Massachusetts General Hospital which was the official affiliator, but in addition six universities in the Boston area have very close relationships to the center so that it truly represents a multi-university center.

We have 100 professionals representing 15 disciplines at the center only a few of whom would have been there had it not been for the center and most of them would not have been in the field of retardation.

The advantage of the center is that not only the professionals represented, but in the fact that it has made it possible, through State-supported positions, the training of people of highest professional competence.

We have now waiting lists for State positions in the professional field that had been vacant for 10 years.

In addition, we have found that there are 1,000 college students who have had contact with the center during this last year. We have found that some who came with greatest reluctance and fear and strangeness to the field of retardation have become the strongest supporters and have shown the strongest interest in the field.

I might say what are the requirements to make such a center work? I would say there are three. The university has to show an interest. That is, the department head or dean must be willing to offer university appointments to qualified people and they must give indication that they consider this an important enterprise.

We have found that all of the deans in the universities which we are associated with have done this to an admirable extent.

Two, the program must be multidisciplinary. That is, if one tries to develop a single discipline such as medicine or psychology and the other disciplines are not strongly represented it is not going to work because if one tries to provide services of good quality in one discipline, if another discipline is lacking the people in the first discipline won't stay.

People who want to help patients won't stay unless they feel that comprehensive services are being provided.

The third is that there must be support of the type which has been outlined in this legislation. Once such support for professionals is provided we can then utilize other sources to great advantage in our instant State support.

Senator **Kennedy**. Very good. That is a very good answer.

Let me ask you, in light of the new student interest and the greater attention of the universities, how you evaluate the effort being made by this kind of arrangement at the Fernald School? How do you relate it to the overall problems of retardation?

Dr. MOSER. I think perhaps Miss Fraser's reference to the diminishing waiting list is already one evidence. We are part of the comprehensive mental health plan or mental retardation plan in the State.

The University-Affiliated Center has been helped by this plan and in turn has helped to plan the function.

Perhaps the best answer I can give to the question is a completely unanticipated result of these programs. We had anticipated that professionals would come to the institution but we have found that college students not only have been there as students but we have been able to attract a great many of them to work in the institutions as attendants.

I think we have been able to overcome this great shortage of people to look after the retarded by attracting to the State school, in rather low-paying positions, college students who want to work there because it means something to them.

The reason that they came is that we have a highly structured program with excellent supervisors where the students can see that their actions make a difference to the patient. So that we have career people who are not career employees but who will spend 2 or 3 years at an institution.

I think this perhaps is the greatest evidence to me that the program has reached the community.

Senator KENNEDY. Would you please elaborate on the training aspects of the present legislation with respect to the affiliated facilities?

Dr. MOSER. I think the greatest point that is encouraging to me is that we are attracting people of high caliber who would otherwise never have come to the field. In a number of instances it has been so clear and we are attracting people in areas that are usually not talked about but who are extremely important such as occupational therapy, physical therapy, recreational therapy. Those are disciplines that had a very limited role in the past but now as part of this multidisciplinary center approach, take care of patients not in a specific limited way but become part of an overall network for services for the retarded.

Dr. GIBSON. May I add to this, Senator Kennedy, I think that universities have been seen as the bastions in areas for training in a graduate specialty.

I think both the House and the Senate has been rightly concerned that universities perhaps did not accentuate or bring to light the needs within society of people who can benefit from an altered training role, persons where the university puts accent on the types of capability needed to accomplish the job role rather than the other more esoteric elements of an overall education. And with these programs we have in a number of areas made breakthroughs into the university participation in the training of people who will work with a family which has a retarded or handicapped child, at an early age in their home, to people who will become cottage parents in communities and in institutions, to people who will develop skills along the physical education area in what we call developmental or remedial physical education, who take as their prime target area of training the needs of the developmentally disabled.

I don't think we would have seen this occur without this particular legislation.

Senator Kennedy. Let me ask you this question: You have spoken of the benefits the program brings to the institution, in terms of the new manpower which becomes available to the institution. You mention that staff positions are now filled which had been unfilled before. You talk about the advantages to the universities in terms of the new interest they are getting from students and the cross-fertilization of ideas under the interdisciplinary approach.

But how are we benefiting the child? Are we getting any direct benefits to him, or are the benefits indirect?

Dr. Moser. I think the benefits are quite direct. I think we all know that the level of care in the institutions is very inferior still and it would be foolish to say that we had solved the problems at our institutions.

But we have in a number of areas made very great gains. We have four or five programs that can be used as models anywhere.

I think we are in the process of eradicating the bad wards and the most important element I think is the development of community services.

I think we have always emphasized the need for community alternatives for institutional care but these community alternatives require skilled professionals interested in this field, experienced in this field, to make them go.

Once we have that, a bright professional, we can then affect by teaching nonprofessionals a hundred retarded individuals and we have seen this on a number of occasions.

I think the center has a very great value in this respect.

In regard to our particular center, I would like to emphasize that we are part of a regional plan. We serve a particular region of Massachusetts and we take anybody who comes, rather than those who appear interesting. The area that we serve includes low-income areas in Cambridge and Somerville and part of Boston so that I think that our center is getting to the high concentration areas of need that the administration was referring to before.

Senator Kennedy. In discussing services to the community, would you please elaborate on the geographical distribution of the university-affilitated facilities?

Dr. Gibson. I think perhaps Dr. Cochran will mention that we did enclose, for your consideration, two maps with my prepared statement of the country which show the geographic distribution.

Dr. Cochran. Senator Kennedy, I think Dr. Gibson and Dr. Moser have in part answered this question, but I think I can give you a specific example of what happens in a segment of the Nation that does not have such a facility available.

The people requiring service are there and the services have to be brought to them. As far as the provision of these services one cannot send trainees some distance to get the appropriate training.

In the City of Houston, which has now approximately 1.6 million persons, they have only one facility in which a mentally retarded child can be evaluated at the present time. This is our child development clinic which is part of Texas Children's Hospital.

It is operated on a service grant. We have submitted an application to be a university-affiliated facility.

At the same time that we provide service——

Senator DOMINICK. Let me interrupt you right there. You said the city of Houston only has one retardation facility?

Dr. COCHRAN. At the present time, Senator Dominick, all mentally retarded children who are receiving comprehensive evaluation are being referred to one facility.

Senator DOMINICK. You have no outlying community clinics and health centers?

Dr. COCHRAN. These are being developed but they can only be developed in a fashion being proposed by the Texas comprehensive mental health, mental retardation plan.

Senator DOMINICK. Why? In Denver we have five already.

Dr. COCHRAN. It is a matter of inadequately trained personnel and insufficient personnel.

Senator DOMINICK. I don't think Texans are any dumber than they are in Colorado.

Dr. COCHRAN. No, they are showing the interest, we have had excellent cooperation by the universities in the Houston area and outside of Houston.

In the preparation of our grant application they have predicated their interest on the fact that there would be a new dimension to their training program which this would provide.

In other words, as has been pointed out, the interdisciplinary approach to the developmentally disabled or mentally retarded individually can really only be properly accomplished in the interdisciplinary setting.

The other routes have been tried and they have not really been successful. The universities have found in this type of legislation, a vehicle by which they can learn to work on an interdisciplinary basis and an interinstitutional basis to develop programs in communities for the mentally retarded.

Another instance in which this approach, this interest, in Texas has been recently manifest is in the establishment of the teacher training program for Headstart which is operated out of Texas Southern University, on the basis of the fact that the community had been encouraged to go ahead and develop this type of facility, and using as a foundation the interdisciplinary clinic setting that we have proceeded to develop these programs.

This is why in our immediate area of 1.6 or 7 million, plus the entire State of Texas, which is 11 million, the lack of the university-affiliated center not only hampers the development of the community-based developmental centers which are part of the comprehensive plan but the development of model programs within a given city.

So these have to be distributed geographically; so to speak.

Senator KENNEDY. What percent of the retarded in Houston are being evaluated?

Dr. COCHRAN. We see approximately 400 new patients a year, plus we carry another 300 or 400 over from year to year because there is no facility in which they can receive on-going care.

The Association for Retarded Children, with whom we work very closely, and the cerebral palsy group that we are trying to develop, and other community agencies have expressed great interest in this but they do not have the trained personnel to do the job which they feel should be done. They look toward this as a means by which all of the disciplines can do a better job and all the agencies can operate more effectively.

But as far as the number that are not receiving evaluation, the superintendent of schools recently stated that he could probably identify 10,000 children with developmental disabilities who were actually failing, they had actually gotten into public school but were failing, and who need the types of services that can be provided only when we have sophisticated training facilities.

Senator KENNEDY. Is the 10,000 figure for the Houston area?

Dr. COCHRAN. The Houston area. As far as the rest of Texas is concerned, there are other areas that have shown interest in developing facilities and there is no doubt but what more than one will be required in Texas. Because you cannot get trainees very frequently unless you can provide training centers close to where these people eventually are going to want to live.

Only in this manner can you get interest generated in work with the retarded, if you can provide training where the people are hopefully going to work.

Senator KENNEDY. Let me ask, Dr. Gibson, in terms of the national need and the interest shown by the universities, what resources are really necessary to meet this problem?

In terms of your own experience, your conversations with university personnel, their reaction to the programs that have been developed, our ability to develop worthwhile interdisciplinary programs in the facilities that are available—can you give us an educated guess as to what level of resources is needed?

Dr. GIBSON. This is difficult to extrapolate. The universities have become sensitive to the fiscal stress that was expressed by the administration witnesses.

Many of them embarked on programs which they saw representing a tremendous addition to the scope of training that a university could offer. For the first time, in addition to presenting a course within a discipline relating to the problem, perhaps vaguely relating to the problem of mental retardation, they could offer students at different levels of competence an opportunity to pursue learning in this area and to pursue it in relation to students of other disciplines.

The operating cost, however, of such a program, will run anywhere from half a million dollars at its inception to $2.5 million to $3 million at the time that the facility is completed and fully staffed.

While the universities are increasingly showing evidence of their participation and their upgrading of these facilities in the priority list which they present to their State support areas if they are State supported or in priorities for private universities in the continuation of these programs, they still feel perhaps they cannot accommodate or cannot achieve this goal without continuation, as represented in this legislation, both of the opportunity for the universities who would like to have these programs to construct facilities, and the basic support as indicated in this particular bill which has become such a critical issue.

The universities do not feel that they can initiate or develop these programs without this.

Dr. Cohen. In terms of the development of the program at the University of Michigan you get an indication of the extent of the university commitment that precedes the development of a plan and eventual construction of a facility.

When Public Law 88–164 was passed, the University of Michigan was approached to see whether or not they would be interested in developing a university-affiliated center. A senior faculty committee was appointed by the vice president which took quite a bit of time and then decided to move ahead with the development of the university-affiliated center program.

There was some planning grant support both from the Joseph P. Kennedy Foundation and Children's Bureau to assist in the early planning.

In 1966, the regents created the institute for the study of mental retardation, which is our university-affiliated center.

At that time there was a major search for a director and a director was appointed in 1967.

In 1967, we started what I would consider the second phase of our planning. This phase incorporated over 200 university faculty of the University of Michigan, faculty from other State universities, personnel from community colleges, to help develop a plan for an interdisciplinary training program in mental retardation.

We had, in addition to the university personnel, a wide representation from community agencies, from the residential institution, from the State mental health department, vocational rehabilitation, the State education department, local education department.

We worked very closely with the problem areas that were cited earlier both in terms of the large city problem, the smaller city problem, and with the tremendous problem of the retarded in the rural area working with the staff in the upper peninsula.

So, with the university providing a tremendous amount of faculty time, a plan was evolved for the development of an interdisciplinary training program at the University of Michigan.

We have staff commitment from the present university right down. The university at the present time is committing approximately a quarter of a million dollars in university general funds toward the program that we have evolved.

In addition we have funds authorized by section 511 of the Social Security Act, approximately $200,000 at this time. Most importantly, however, we feel that even without a physical facility we have developed a focus for much of the university and State concern with mental retardation. Our involvement is not merely within the university but has very strong community relationships.

Our thought is that we have to work cooperatively with communities and, in terms of Senator's Dominick's concern, at a level that a community can support a program.

If you go in as a university with $1 million in grants and try to generate something, you can generate a lot of hostility because the community feels they could do it better and if they got the $1 million they might be able to do more of what they want.

We work on the basis of what the community agencies are willing to support. If there are appropriate funding agencies that have matching funds we would apply for that, but working in strengthening existing community agencies throughout the State mental health program, through the community programs, through residential programs.

So that while I mention the quarter of a million dollars that the university is putting in this year I don't believe that anybody has really added up the total university dollar commitment or staff commitment to the program.

Senator **Kennedy**. One of the provisions of this bill—title II—is designed to provide continuing funding for these university centers.

Do you think that such funding is necessary, or do you find that, once the Federal funds become available to establish a facility, it is unnecessary to continue funding?

Dr. **Cohen**. I think continued funding is required. I believe there are certain areas in which funding is not covered by any of the areas.

We run into the problem of basic operating costs, the costs not directly related to the training of students or to the salary of faculty, either the trainees or the trainers.

In this area additional help is required. I think your bill would meet the need of the university training programs. In terms of the total operation of most of the programs the figures represent a small part of the total operation, the costs that are not covered by any other program.

Senator **Kennedy**. Senator Dominick?

Senator **Dominick**. I just have a couple of questions.

Dr. Gibson, given the probability of funding of programs as was mentioned by Mr. Black, do you still think that you would support the concept of funding for the developmentally disabled in addition to the mentally retarded?

In other words, my thinking is that if we get no more money than we have now and you expand the definition of mentally retarded, the effort on behalf of the mentally retarded might go down?

Dr. **Gibson**. I really think the name is a rather delicate thing that your committee will have to deal with.

I think if we ask people from the back of the room to give their definitions we would need a computer to deal with the outflow.

The name, I think, though, is a rather choice one if a person does not want to, I guess it is safe to use the word "prostitute" oneself to performance of services to families that do not delineate themselves in a nice, easy, handy category.

We have to realize that there are many children with mental retardation who do have an emotional illness overlay which may not, however, be the primary management problem.

We do have to realize that there is a tremendous association between the occurrence of intellectual maldevelopment and appropriate or other related physical deformities or disability.

Senator **Dominick**. Isn't it the fact that the centers now are treating these people anyhow?

Dr. **Gibson**. Some of the centers are indeed treating and dealing with this wide spectrum. They are also, however, dealing with these children who pose problems within our school system under the title of learning disorders. So that we have tendered in our definition to use the World

Health Organization definition of mentally retardation which is broader in scope than a number of the areas that we work in are willing to accept as being mentally retardation, so that in order to avoid conflict of interest we feel that the term developmental disabilities is a reasonable term.

We do not, however, preclude from this that these centers would in any way become a threat to crippled children's services.

If anything, they would tend to support through this term maternal and child health programs within most States. This is not something I think we can decide as a university-affiliated center group but I think it is certainly a significant point that you will have to consider as you hear the various witnesses that relate to this particular legislation.

Senator DOMINICK. I know from personal observation, having served as a trustee in one of these clinics, that many families are automatically tense and unwilling to cooperate if you consider a child is mentally retarded, whereas, if you consider the same child as developmentally disabled they are perfectly willing to come along and get some help under those circumstances.

It is very difficult to distinguish the two. Will you agree with that?

Dr. GIBSON. We tried to set up an experimental model at Ohio State. We have two intake valves, one labeled mental retardation and the other is labeled developmental disorders.

We have really not been able to find any differences in the two populations or in their reactions to the wording.

Now when I addressed the AFL-CIO in my local area I certainly picked it up there. I think within America there is still a segment of population that is very concerned with the term "mental retardation".

I think those of us who work with the problem see its dimensions and see rays of light for solution. However, the term does not become nearly as important as the opportunity for some of the problem solving.

Senator DOMINICK. That is another kind of philosophical question here.

If the universities are unwilling to develop these interdisciplinary centers for this purpose on their own, doesn't this mean that they are not placing very high priority?

Dr. GIBSON. If you look at the program, and we have done this at Ohio State, you ask yourself a number of questions about the effectiveness of your university in training graduates as it is presently constituted in isolation from the many particular disciplines and you rank this and relate it to dollar cost, you find there is a very close tie in between the ranking that you have and almost any measure you want to use with the amount of dollars available per student.

This kind of program will offer universities two things: One, it will bring more dollars per student because we are dealing with a wide range of students. It will offer an educational opportunity to that university that will set them aside from perhaps four or five or six other universities whose total operation is departmental and college related.

So that the feeling I think among most of the universities is that if they can support these programs this makes a breakthrough in their operational outline which could not be achieved by any other means.

If the funding is not going to be available I think there will be a heart-rendering type of reaction on the part of universities who saw this as perhaps one of the opportunities to bring into universities areas of concern that had not been previously categorized as appropriate.

We have to remember that in the development of universities that once upon a time psychology was like this program until it established its worth, its value, and its intellectual support to training, and here again, I think that we are at a period where the emotional blush on this program is receding but where the intellectual build-up is occurring and does need support.

Senator DOMINICK. Yet you say in your statement that "The cost of staffing is such that although State and local support is vigorously sought it is clear that the Federal Government must be prepared to carry the major share of the initial funding load if the mandate of the center is to be achieved."

What you are saying is that unless the general treasury pays for this initial funding load the universities don't put that priority on them.

Dr. GIBSON. This is true. Also, it is not followed by other evidence that we have and again the acceptance by the group that we represent that this is a diminishing ratio.

I do not think that universities will spontaneously generate these programs although there is one State that has become so upset with the delay of release of funds that they are moving actively in this direction.

I think the majority of the universities within the Nation will need this type of stimulus support to allow the construction of such facilities and development of such programs.

The outrun of this, the increasing university, State and community support for these programs, I do not see as a problem, at least in Ohio. We have a lot of interaction between our program and the State developmental and planning people.

The program is one of the recommendations of their Mental Retardation and Planning Citizens Committee so that there is no doubt in my mind that the citizenry of the particular States are anxious for their success.

But we are representing a large number of universities that do not have even the initial plan underway and do not see any opportunity within their geographic area without this legislation to ever get such a program going.

Senator DOMINICK. I think I have made my point. The problem as I see it is that there are a great number of very good programs. I happen to place a high priority on this one. There are a number of good programs on which the local areas are not willing to put a high enough priority of funds.

Everybody says, "It is easier to get at the general treasury than in the local area so we will come back here to get it."

My point is should we not put more emphasis the other way?

Dr. GIBSON. This is a much broader sociological question than I would be prepared to comment on. I realize this is a continuing concern. However, I would like to comment that the single project grant approach is something that I hope this committee will weigh and scrutinize before making any decision.

I think this could be catastrophic in terms of the development or an opportunity for development of this kind of activity.

Dr. COHEN. I believe if you will look at the Federal money as seed money and university-affiliated centered programs as a way to really focus on the needs of the community and to provide leadership for the various communities, that the end result will be an increasing State and local expenditure on the mental retardation programs.

Senator DOMINICK. I would think this would be just great if in fact it moves that way.

Dr. COHEN. It is moving in that direction in Michigan.

Senator DOMINICK. It is seed money and then everybody comes back and says, "Unless we have the money we can't keep it going."

Senator KENNEDY. Thank you very much.

Our next witnesses will be a group of representatives of the United Cerebral Palsy Associations.

Their principal spokesman this morning will be Mr. Sherwood Messner, who has been a leader in the voluntary health field for many years and is nationally known for his work in community organization.

As I indicated in my opening statement, Mr. Weinrich is here to speak for those of the disabled who are unable to speak for themselves. Mr. Weinrich has a masters degree in social casework and is the associate director of one of the most significant UCP departments.

Also with us this morning is Dr. Elsie Helsel, who is a geneticist by profession, and the Washington representative of UCP. She is the mother of a 23-year-old cerebral palsied son.

Before we begin, let me also take this opportunity to commend the UCP for the extremely useful assistance they provided the committee in connection with the communicable disease control and vaccination assistance amendments, which passed the Senate 2 weeks ago. The UCP has made a major contribution to our national program to combat German measles, and I look forward to hearing their views on the bill before us today.

STATEMENT OF SHERWOOD A. MESSNER, DIRECTOR, PROFESSIONAL SERVICES PROGRAM DEPARTMENT, UNITED CEREBRAL PALSY ASSOCIATIONS, INC.; ACCOMPANIED BY ERNEST WEINRICH, ASSISTANT DIRECTOR, PROFESSIONAL SERVICES PROGRAM DEPARTMENT, UNITED CEREBRAL PALSY ASSOCIATIONS, INC.; AND ELSIE D. HELSEL, PH. D., WASHINGTON REPRESENTATIVE, UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

Mr. MESSNER. Thank you. We do appreciate the opportunity to appear in support of S. 2846, the Developmental Disabilities Services and Facilities Construction Act of 1969.

With your permission, I will not read all of the written testimony as presented to the committee but would like to highlight a few of what we consider to be the most important things, from our standpoint, at least.

Senator **Kennedy**. Your prepared statement will be included in its entirety in the record.

(The prepared statement of Mr. Messner follows:)

PREPARED STATEMENT OF SHERWOOD A. MESSNER, DIRECTOR, PROFESSIONAL SERVICES PROGRAM DEPARTMENT, UNITED CEREBRAL PALSY ASSOCIATIONS, INC., ON BEHALF OF UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

SUMMARY

Suggested changes in the bill

Page 1, line 2–3—change from "persons affected by mental retardation and other developmental disabilities"; change to read "persons affected by developmental disabilities as defined in the bill".

Title I, page 6, line 4–5—change from "services to mentally retarded and other developmentally disabled persons"; change to read "services to developmentally disabled persons".

Page 6, line 5–6—change from "leaders in the field of service to the mentally retarded and other developmentally disabled"; change to read "leaders in the field of services to the developmentally disabled".

Page 9, line 9–10—change from "services and facilities for persons with developmental disabilities associated with mental retardation"; change to read "services and facilities for persons with developmental disabilities".

Page 9, line 15–16—change from "persons with mental retardation and other developmental disabilities"; change to read "persons with developmental disabilities".

Page 21, line 11—after "sheltered employment" add "transportation".

Page 21, line 13–14—change to read "information, referral and follow-along services".

Title II—change the language throughout from "mental retardation" to "developmental disability".

INTRODUCTION

Mr. Chairman and Members of the Sub Committee on Health, I am Sherwood Messner, Director of the Professional Services Program Department, of the United Cerebral Palsy Associations, Inc., the national health organization on whose behalf I speak.

I live in New Rochelle, New York.

I should like to introduce my colleagues with me this morning—Dr. Elsie Helsel, parent of a cerebral palsied son and part-time Washington Representative for United Cerebral Palsy and Mr. Ernest Weinrich, Assistant Director, Professional Services Program Department.

We appreciate very much the opportunity to appear here today in support of Senate Bill 2846, the Development Disabilities Services and Facilities Construction Act of 1969.

With your permission we should like to make a brief summary statement and then highlight points from the written testimony you have before you.

Language of the bill

We are particularly pleased with the language chosen to describe the group of individuals to be served by the Bill, namely the Developmentally Disabled. We think this choice of language represents an important advance in the thinking and knowledge of the needs of seriously disabled individuals and progress in the realization that agencies with a categorical focus can work cooperatively to provide the comprehensive programs that are required.

We believe this language will encourage the development of more effective, efficient, coordinated and consolidated service programs whose primary purpose is to serve individuals with related needs rather than to serve diagnostic labels, such as cerebral palsy or mental retardation. In view of our greater knowledge and experience, we now know that such labels tell us nothing about the program needs of individuals or the services which must be developed to meet their needs. We now know that the program needs of the cerebral palsied and the mentally retarded are similar but not identical. Some programs for these groups can be combined effectively. Others must be developed separately.

We do not share the concern of some that the use of the broader term, "developmentally disabled," will open up services to large numbers of individuals not intended for service under this Bill. United Cerebral Palsy has for years opened its Developmental Day Care Centers to those seriously handicapped individuals for whom there was no other appropriate service in the community. We have not been overwhelmed with requests for service. We have learned that individuals with serious disabilities share common needs regardless of diagnostic labels. We are satisfied the protective limitations in the definition of the developmentally disabled in the Bill are quite adequate to restrict services to the group intended—those whose condition originates in childhood, is expected to continue throughout life, constitutes a substantial handicap to the individual, and for whom services are not available through any other resource.

Comprehensive range of services spelled out in the bill

We heartily approve the comprehensive range of services spelled out in the bill. We believe such provisions will make possible the filling of gaps in service programs for the developmentally disabled—gaps which have diminished the effectiveness of already existing services because there has been no way to maintain gains achieved in earlier programs. To cite an illustration, there have been therapy programs for children for some years. However, at the adult level there are only limited services to provide therapy that would maintain gains already achieved or even to provide essential medical supervision. We know of too many instances where children, after years of training and education, have been brought to a good level of functioning and performance only to be terminated at the age of eighteen or twenty-one because of age and agency limitations. Without sheltered workshops or adult activity programs these young adults regress and are unable to capitalize on gains and skills acquired in earlier years.

Although our overall reaction to this legislation is enthusiastic endorsement, we do have a few concerns.

Permissive language

We are troubled by the permissive language in some sections of the Bill pertaining to the inclusion of the developmentally disabled other than the mentally retarded in the services that can be included in the State Plan. Although Section 130 under Title I clearly states that "The purpose of this part is:

(a) to make grants to assist the several states in developing and implementing a comprehensive and continuing plan for meeting the current and future needs for services to persons affected by developmental disabilities; and

(b) to make grants to assist public and non-profit agencies in the construction of facilities for the provision of services to persons affected by developmental disabilities."

In four other places in Title I phrases such as "persons affected by mental retardation and other disabilities' and "persons with developmental disabilities associated with mental retardation" *would permit interpretations which imply that the developmental disability must be associated wih mental retardation and that those with developmental disabilities other than mental retardation may, but not must, be included in the State plan for services.* This would continue the exclusion of some of the severely disabled cerebral palsied who are not mentally retarded but who do have similar service needs.

We should like to suggest that in the interests of clarity and consistency the term "developmental disability," as defined on Page 20, lines 20 through 25 and Page 21, lines 1 and 2 in the Bill, be used throughout without qualifying phrases. Otherwise, even under this measure we can envision the developmentally disabled, other than mentally retarded, again assigned low priority for services in the State plan.

State allotments

In Section 132 on Page 3, lines 17 to 22 the Bill states "In determining . . . the extent of need in any State for services and facilities for persons with developmental disabilities, the Secretary shall take into account the scope and extent of the services specified, pursuant to Section 134 (b) (4), in the State Plan of such State approved under this part." We would urge the addition of a built-in incentive factor in the formula for States that elect to include in their State Plans other categories of developmental disabilities. Otherwise, when funds are in short supply, these groups will find themselves as before—lowest on the priority list. Although their numbers are small their needs are great. Without this feature, we believe there would be further fragmentation rather than coordination of services. Agencies serving groups that are left out are compelled to develop services to meet needs of these groups. The non-ambulatory person with cerebral palsy is far more difficult to serve than the individual who is ambulatory. This group as a whole is hardest hit by a lack of services, and yet has been low man on the totem pole for some time.

National and State advisory councils on services and facilities for the developmentally disabled

We are pleased to note that there are to be on the National Advisory Council, representatives from leaders in the field of services to the mentally retarded and the other developmentally disabled persons. We are also pleased to note that consumers or their representatives are to be represented on the Council. We should like to respectfully suggest that this same pattern of membership be repeated and be specifically stated for the State Plan and State Advisory Councils on services and facilities for the developmentally disabled.

We ask that the membership be specified in the Bill. We have learned through unhappy experience with the Partnership for Health Advisory Councils where neither the mentally retarded nor the cerebral palsied are well represented.

Revision of State plans

We heartily endorse the provisions for updating the State Plans and hope that the regulations for this Section will be quite firm about the review, evaluation and updating of the State Plans at least annually.

In most states the mental retardation planning effort dates back to the 1963–1965 period. Taking Ohio as a typical example, plans (except for the construction plans) have not been updated since that time. In Ohio some progress in implementation has been made—including an innovative approach to protective services. This is one of the services recommended in the Report of the President's Panel but listed for the first time to our knowledge in this Bill. However, in Ohio an attempt ot legislate the continuance of the Citizens' Committee which drafted the Plan with paid staff and funds for Committee meetings was defeated. Unless some funding for continuing work on planning and implementation is forthcoming, the Ohio Plan will gather dust and much valuable and costly effort will be wasted.

Another even more relevant reason for requiring an update of the plan is that the plans were drafted specifically in the language of mental retardation. Although many of the developmentally disabled are mentally retarded, they are not always included because they were tagged with another label. To be consistent and to make for more effective and efficient coordination of services to the severely disabled group, it would seem appropriate to bring the language in the State Plans in line with the language in this Bill.

Groups to be included in the State plan

On Page 9, lines 9 to 16, we would hope that in this Section also the intent is not to indicate priorities but to consider the needs for services of the total group. As we have stated repeatedly the non-ambulatory group and their families are often the ones left unserved in the community. Only now are we beginning to see this group added to the waiting lists for institutional placement. In order to preserve the intent of the Bill, to serve all of the developmentally disabled, we should like to respectfully suggest that the qualifying phrases be eliminated and the single term developmental disability be used as defined in the Bill.

Services to be covered

On Page 21, lines 3 to 14 again we would like to commend the Committee for its wisdom in defining "services" so that at long last it will be possible to provide a truly comprehensive program for the developmentally disabled. This will make it possible to fill the gaps which unfortunately have accrued because of our fragmented approach to services. Seriously disabled individuals and their families have a continuum of need throughout their lives. It is both costly and inefficient to provide excellent services during the school years, for example, and then not follow through with workshops or work activities programs for adults. Or, to provide very costly therapy programs for children through age 18 or 21 to achieve maximum functioning and then, because there is no maintenance therapy service, to permit the person to retrogress, to allow his contractures to take over, to watch him become a total bed care case because there is no encouragement for self-care.

We should like to suggest just the addition of two services to those already listed: transportation and information and referral services.

Transportation is a major problem in the provision of services to the disabled, particularly for the multiple handicapped. We urge that transportation be duly considered as one of the important services for which federal and state funds should be used in a total comprehensive program.

Concerning information and referral services, we at United Cerebral Palsy have found frequently that the developmentally disabled and their families cannot thread their way through the maze of services available to them. We also have found that they frequently are dropped from a service because it is inappropriate or the agency finds that it cannot manage such a severely disabled person. There may be no immediately obvious service to which to refer and thus the individual falls between the cracks of services, gets lost . . . sometimes for years.

Information and referral is not enough. We find another component, a "follow-along component" is vital. The agency giving this service to a seriously disabled individual and his family needs to form a partnership for life in order to be sure that services continue and to avoid crisis situations. Even if at some period there are no organized services to meet needs, continuity of contact with the individual and his family should be maintained.

Title II—University-affiliated facilities

Even though most of the developmentally disabled would be included under the present language (mentally retarded—which for purposes of this part includes other neurologically handicapping conditions found by the Secretary to be sufficiently related to mental retardation to warrant inclusion here), in the interest of consistency, we should like to suggest that the language in this Section of the Bill be changed throughout to "developmentally disabled."

How this bill will help the cerebral palsied; definition of cerebral palsy

Cerebral palsy is the general term applied to a group of disabilities caused by injury or damage to the developing infant brain. It results in impaired muscle control and function. However, this is not a single disability and almost never occurs alone but in combination with other problems. About two thirds of the cerebral palsied are also mentally retarded; one-half have speech and communication problems; about one-third have visual disorders; 20 percent have hearing difficulties. An undetermined number have learning difficulties associated with perceptual and conceptual difficulties.

Not everyone with cerebral palsy has all these defects. One in seven may be so little affected that he requires no special assistance. Others are totally incapacitated. Most have a combination of symptoms. They need planned coordinated treatment and training, much of it extending over the greater part of their lives.

They need services that cost more than most families can afford, a multiplicity of service programs that no single health agency can provide, such as: physical, occupational, speech and hearing therapies; special education programs; developmental and day care centers; vocational guidance, training, work-ready programs; employment; social and recreational activities; eye care; special dental care; braces; drugs; sometimes surgery; and ongoing medical supervision. Nearly all need special transportation if they are to get to available services.

But with cerebral palsy, it is not just those who are handicapped who need help. Parents and families need help too: counseling and guidance; instruction in how to care for a handicapped child; supportive services to maintain home and family stability during crisis periods.

History of United Cerebral Palsy Associations, Inc.

UCPA was born out of these needs. During the 1940's groups of parents and a few professionals in a scattering of communities joined their efforts to get medical and educational help for children whose future seemed hopeless. Services for children and adults with cerebral palsy evolved from their concern, their action, and thus. In 1949 the national organization was founded.

What does UCPA do?

In the beginning, UCPA affiliates stressed treating what was physically correctable—through physical, occupational, and speech therapy, with braces or surgery—and learning. Reluctant public school authorities were persuaded to accept cerebral palsied children in existing facilities, where possible. United Cerebral Palsy established special education classes when necessary and pioneered many advances in this field.

Recognition that therapy programs which primarily focused on improving physical impairments failed to benefit many, led to a broadening of emphasis. Some groups organized recreation programs for children and adults. Others started sheltered workshops for those whose disabilities prevented them from working in a competitive environment.

The knowledge that cerebral palsied children lag in development behind normal youngsters has more recently stimulated the establishment of nursery, preschool and developmental centers, special "head start" programs for children with multiple handicaps. Concern for more severely disabled adults—and their families—has led to day care programs for adults, organized services to provide relief for overburdened families. There are also work and social activity programs.

In 1969 there are 45 UCPA state affiliates and 259 affiliates in local communities including the District of Columbia. These affiliates offer a wide range of care, treatment and training programs for persons with cerebral palsy. Large affiliates in major population centers provide or support almost every type of service needed. Others purchase services from appropriate local agencies. The aim is to see that services are provided but not duplicated.

But there are gaps in the service program. UCPA does not reach all who need its programs. Many are unknown because cerebral palsy need not be reported to health authorities. Many severely disabled persons are in institutions for the retarded. Those whose major problems are deafness or blindness may be receiving services from agencies concerned with these health problems. Others who have previously received UCPA's services have reached "maximum" age limits and have "graduated into oblivion." In urban ghettos and in rural communities individuals with cerebral palsy may be isolated, living out their years behind closed windows or in front of TV screens, because UCP services are unavailable or unknown to them.

These are the continuing challenges that UCPA faces in the effort to carry out its primary responsibility of meeting the physical, psychological, social and intellectual needs of cerebral palsied children and adults. To carry on this mission requires a partnership with other services, both public and private. We see the Developmental Disabilities Bill as having tremendous potential for helping us to carry on our mission.

How this bill can help the cerebral palsied

UCPA has been trying to meet specific problems confronting the developmentally disabled that other agencies have failed to meet or do not care to address. It has been our policy not to duplicate already existing services that are adequate. We see our role as that of pioneering in new services which are needed and lacking. When such a needed service has been identified we try first to develop techniques and practices to meet the need. If we can demonstrate to our own satisfaction that cerebral palsied can indeed benefit from such a service and that there are sufficient numbers to warrant the service, we then try to search out the tax-supported agency which most logically should offer the service. We have done this with our diagnostic and evaluation clinics, with our therapy programs and with some of our educational programs for the more able cerebral palsied. This program policy then continually frees UCPA money and staff for new program development.

We should like to tell you briefly about three specific areas in which we now see a need which this Bill could help us to meet.

Of the approximately 700,000 cerebral palsied individuals in the United States, about 280,000 are estimated to be within the normal intelligence range. However, about 33,000 of these individuals are so severely physically handicapped that they cannot even work in sheltered workshops. They do not qualify for other state and federal programs. They need help in managing themselves and their personal affairs. For want of a better name and because of the relationship to existing patterns of similar but not identical services for children and the elderly, we call these Protective Services.

Protective Services are primarily case management services of a social and socio-legal nature. They help individuals maintain themselves in various kinds of special living arrangements rather than being place in institutions. Protective services assist the multiply disabled to get those community services to which they are entitled and to protect their civil and human rights. The Developmental Disabilities Bill can certainly help in establishing protective services not only for this group but also for the entire group of the retarded who need such services—especially after parents die. A protective services program should include for those of the retarded group incapable of making their own decisions, a public guardianship program so that parents will no longer be haunted by the question "What will happen to this child when we die?"

Approximately 420,000 of our cerebral palsied individuals are also mentally retarded. Obviously this group would stand to gain much by the passage of this Bill. Some of this number can, of course, be served by other agencies serving the retarded. However, it has been our experience that as the physical handicap becomes moderate to severe, these individuals are quickly dropped from programs that would otherwise be appropriate for them. The multiply disabled are the last to be added to programs as they are developed, regardless of whether they are educational, training, recreational programs, sheltered workshops—and these disabled persons are the first to be dropped when budgets get tight.

Developmental day care programs for children

UCPA has been concentrating attention during the past few years on Developmental Day Care Programs for Severely and Multiply Involved Children. We have learned that if we can get these children into stimulating programs at a very early age and if we can get them into proper supportive equipment so that they can attend to their world and their lessons, they can learn.

We should like to call your attention to the picture attached to your Testimony to show what we mean. The youngster lying on the litter seeing not much more of her world than the ceiling or the wall of her room isn't very hopeful material for a teacher to try to teach. This child had been managed from that supine position from the time she was an infant, except for brief periods for feeding in the relaxation chair shown in the next picture. It took time at our Indianapolis Center to work her up from the position of lying in the litter most of the day to a semi-erect position, and then gradually to an erect position so that she could be properly supported as you see her in the last picture.

If you will note her head is supported so that her visual field is enlarged and she can see her world. Her elbows and trunk are supported so that she has functional use of her hands and she can make some effort on her own to hold up her head. Her body is in good alignment so that she feels secure in space. You can tell by the expression on her face that this little girl is now ready to learn.

UCPA has about 3,000 of these children in its Developmental Day Care Programs. The cost is about $1,700 per year per child, including transportation, where these 5-day-a-week programs are offered. Many of our affiliates cannot afford five-day programs for this group; nor can they serve all of the children who could profit from such a program. We estimate there are about 10,000 such children in the United States. The Developmental Disabilities Bill would help us reach and teach more.

I might point out that for children as severely handicapped as is this young lady, the alternative to providing Developmental Day Care Programs in the community is costly and prolonged institutionalization.

In Illinois there are two excellent facilities providing what we would consider adequate institutional care for a person so handicapped. The cost for such programs is approximately $10,000 per child per year. Contrast that with the $1,700 for which we can program these children at the community level and which allows them to live at home with their families.

HIP and HIST programs

While we have the picture of this little girl before us, we might point out that this type of equipment and management pattern is appropriate for severely disabled children and adults regardless of where they reside. There are many such children in state schools for the retarded. This Bill, as we understand it, would also provide the authority for the Hospital In-Service Training programs and the Hospital Improvement Programs which have provided the vehicle for our UCPA Nurse Consultant to participate in seminars and training programs for patient care personnel in institutions for the retarded. UCP has used these funds to train ward personnel and others in the techniques of care and the design of supportive equipment. As we all know funds for these programs have been limited and they have not been able to grow as rapidly as we had hoped. We see this Bill, if it is funded at the level requested, as having tremendous potential for help in improving programming for the developmentally disabled in institutions for the retarded.

Services for severely disabled adults

One of the top priority areas for program development within UCPA right now is services for the severely disabled adult. In our Centers we have not only severely disabled adults whom we served when they were children, but we are accumulating adults who have been served through other programs during their school years. For one reason or another they have not been considered good potential for training through the Bureau of Vocational Rehabilitation and they and their parents turn to our UCPA affiliates for programming.

Trying to develop programs for severely and multiply disabled adults is a challenging business. The day-to-day management and transportation problems alone are almost overwhelming. In addition to the need for year-around activity and work programs, these adults need a number of other services if they are to be maintained properly in the community in keeping with present-day trends. They need specialized housing and follow-along case management services, protective services and maintenance medical services.

A few of our affiliates have developed imaginative programs to meet the needs of this group. Denver, Colorado has pioneered in innovative and unique adaptations of equipment in order to enable severely disabled adults to work in a sheltered workshop situation. Columbus, Ohio has over 100 severely disabled adults in a combined workshop and work activity Center program. New York City has a most interesting developmental program for adults which includes an apartment for training in independent living.

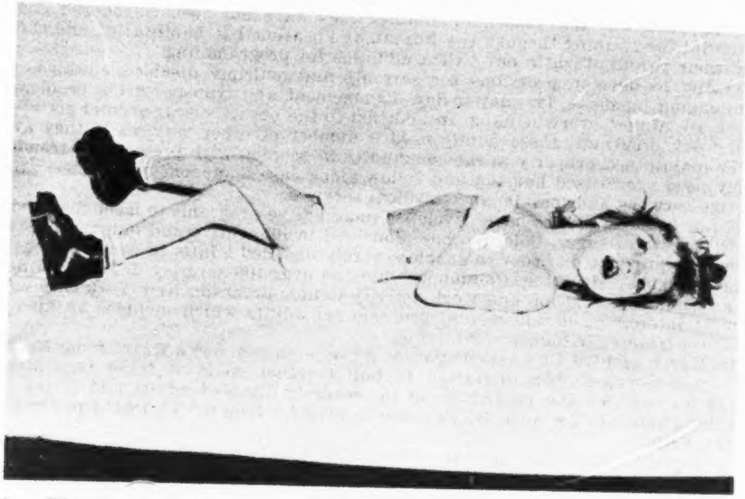
In March of 1970 UCPA will sponsor a Conference under a Grant from Rehabilitation Services Administration to pull together some of these innovative ideas for services and programming for severely disabled adults and to try to develop guidelines for agencies that are looking for help in developing programs in this area.

At present we are serving only about 2,500 adults in some fashion—some in programs scheduled only one day a week. Others meet only a few times a month. It is for this group, where the need is so great, that the expanded service provisions of the Developmental Disabilities Bill could have a really great impact—special living arrangements, day care programs for adults, sheltered workshops with adaptations, protective services. All of these services are desperately needed.

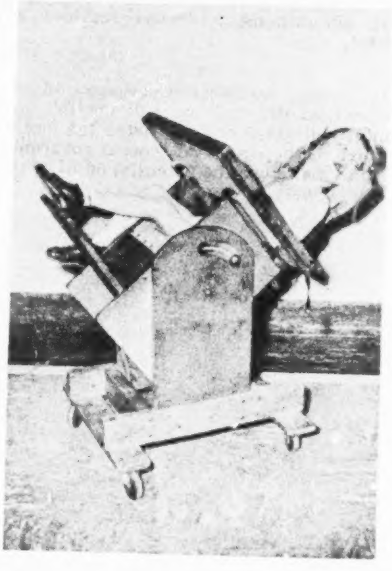
CLOSING STATEMENT

In closing, we feel the passage and adequate funding of the Developmental Disabilities Bill will make it possible to fill gaps in services for the developmentally disabled and to hasten the day when, working together, the voluntary sector and the state and federal governments can provide a comprehensive program to maximize the potential of all of the developmentally disabled.

UNITED CEREBRAL PALSY ASSOCIATIONS, INC.
66 East 34th Street
New York, N.Y. 10016



1. *This is a severely retarded girl who is nine years of age. She has a type of cerebral palsy which is referred to as* tension athetosis. *Both her arms and legs are affected and she is unable to sit alone or to swallow with her mouth closed. Her legs cross because of tension and the pull of a dislocated hip.*



2. *In earlier years she was placed in a relaxation chair as shown above. This chair was tilted at a 90 degree angle and was never placed in a more upright position as she grew older and improved. Because her feet were unsupported, she could not relax and would stiffen her body.*

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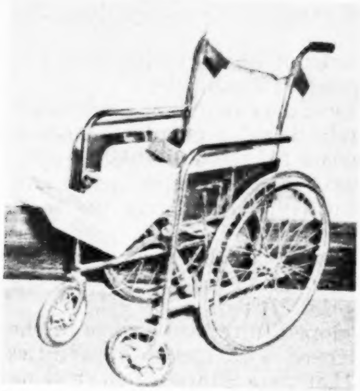
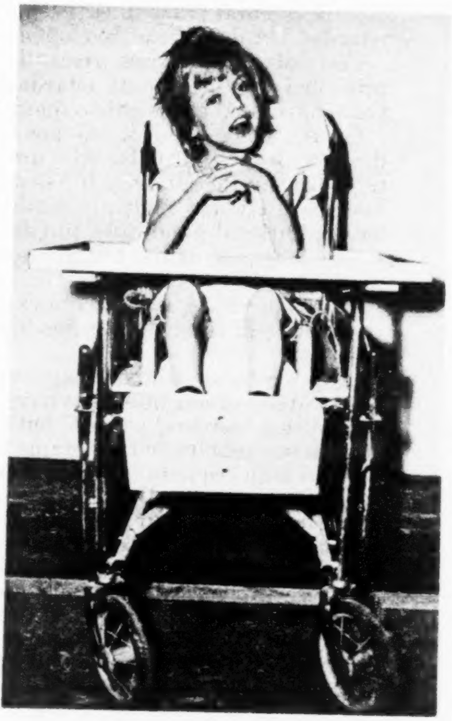
Southern Regional Education Board, Atlanta, Georgia



3. *Above is a wheel chair adapted expecially for her. A 2" web belt is attached to the back struts to permit a gradual raising of the plywood back. The plywood is covered with plastic sponge, then with a washable material. This is to protect her back which has a positional deformity. The plastic sponge neck-pillow is covered with a removable slipcover. It is constructed so that her head is supported at the base of the skull. The plywood seat is hinged to the back support. The depth of the seat is made to fit her and is covered with a plastic sponge pillow which is wedge-shaped, 1½" at the front and ½" at the back. This pillow, as well as the raised foot rest, helps give her body stability and overcome her tendency to stiffen her body. A 2" wood block attached to the foot rest keeps her feet separated. The sides of the seat have hip supports to help keep her hips from turning. Additional stability is obtained by placing soft leather cuffs around her thighs and attaching them to the side supports. These are buckled on the outside of the seat in such a way that she cannot scrape her arms against the buckles. A wide seat belt is fastened across her lap for additional security.*

4. ***The above picture shows her being fed in a semireclining position. If she were fed in an upright position, she would choke, never having been seated in an upright position. As she gains experience and confidence, she can gradually be brought to an upright position.***



5. *Here she is in her adapted chair with a lap tray attached. Note her relaxed appearance and the attempt she is making to support her trunk by means of her elbows as well as to hold her head upright and away from the pillow. Compare her appearance here with that in pictures 19 and 20.*

Mr. Messner. Thank you. We wanted to talk particularly about the language of the bill.

I have been interested to hear the amount of discussion that has gone on in regard to the term "developmental disabilities."

As an organization we feel that this term does represent a relevance of knowledge about the needs of severely disabled people and about the kinds of programs that are appropriate for these disabled people.

After all, the terms that have been used such as cerebral palsy and mental retardation are somewhat arbitrary, particularly the term cerebral palsy.

In fact, some of our medical people don't use this term at all because they feel that it is not descriptive enough of the problems, of the individuals concerned.

However, this is the way it has developed in terms of some of the voluntary organizations that are concerned with specific disabilities and with parents of these individuals that were interested in starting an organization and providing services to the community. We feel that it is of some value to identify various categories, but actually when you get down to the question of services to these individuals the terms really do not mean that much.

I am sure that the committee is aware that perhaps as many as two-thirds of all the individuals with cerebral palsy also have some degree of mental retardation.

However, this means that of the total of 700,000 which we believe to have cerebral palsy in this country about 250,000 are not mentally retarded but do have a developmental disability.

Certainly the services, research and the training that have been promoted by the mental retardation legislation over the past few years have been of benefit to many of the cerebral palsied.

On the other hand, it has not benefited particularly those individuals with cerebral palsy who are not mentally retarded and I have to go beyond that and say it has not particularly benfited some of the more severely and multiply disabled who are mentally retarded but have additional handicaps, physical and otherwise.

The language of the bill, therefore, with the term "developmental disabilities" we would heartily endorse.

We do not share the concern expressed here this morning by others that this will open up the floodgates and swamp the programs and services.

As a matter of fact, our experience would seem to indicate the contrary. Many of our programs have been opened to individuals who are not labeled "cerebral palsied" but who need the services that are available in our centers and programs. For the most part we have not been flooded with requests for these services from such individuals. I think you will recall that Dr. Gibson and Dr. Cochran made the point that you cannot frequently come up with a differential diagnostic label in a young mentally retarded or cerebral palsied child.

One particular thing I would like to emphasize is that when some of these categorical diagnoses cannot be applied until later in the life of the child, this has meant in quite a few instances that services have been delayed. If you have to have a diagnosis of mental retardation in order to take advantage of programs for mentally retarded or if you have to have diagnosis of cerebral palsy for services it means you have lost many important years of early intervention and treatment.

We feel that the limitations on the definition of development disability as set forth in the bill are adequate to restrict services to the group intended, namely:

> Those whose condition originates in childhood, is expected to continue throughout life, constitutes a substantial handicap for the individual, and for whom services are not available through any other resource.

While on the question of terminology I would like particularly to call attention to language in the bill that would seem to us to weaken this terminology.

Specifically in section 130 under title I, the bill clearly states:

> The purpose of this part is, (a) to make grants to assist the several States in developing and implementing a comprehensive and continuing plan for meeting the current and future needs for services of persons affected by developmental disabilities and, (b), to make grants to assist public and nonprofit agencies in the construction of facilities for provision of services to persons affected by developmental disabilities.

However, in four other places in title I phrases such as "persons affected by mental retardation and other disabilities" or "persons with developmental disabilities associated with mental retardation," appear. We feel that this would permit interpretations that were not intended by the drafters of the bill to imply that developmental disability must be associated with mental retardation and that those with developmental disabilities other than mental retardation may, but not must, be included in the State plans for services.

This would continue the exclusion of some of the severely disabled cerebral palsied who are not mentally retarded but who do have similar services needs.

We would lie to suggest that in the interest of clarity and consistency the term "developmental disability" as defined on page 20, lines 20 through 25, and top of page 21, of the bill used throughout without the disqualifying phrases. Otherwise, even under this measure we can envision the developmentally disabled other than mentally retarded again being assigned low priority for services in the State plans.

While we are talking about the State plans I would like especially to call attention to what would appear to be an innovative idea regarding the State allotments.

In section 132, page 3, lines 17 to 22, the bill states:

> In determining * * * the extent of need in my State for services and facilities for persons with developmental disabilities, the Secretary shall take into account the scope and extent of the services specified pursuant to section 134(b)(4) in the State plans of such State approved under this part.

We hope this will be interpreted, as we understand was the intention, as providing a built-in incentive factor to the various States to include individuals with developmental disabilities other than mental retardation, and that some formula can be arrived at so that this will be a real incentive for the State.

We feel that the State mental retardation plans do need updating. In the first place, it has been 4 or 5 years since these plans were formulated and a lot of things have happened in that time.

Secondly, the plans were developed within the terminology of mental retardation. If we are now to move into what we consider to be a much more appropriate term, "developmentally disabled," this language will need to be altered in the State plans. So we certainly endorse this.

We heartily approve the comprehensive range of services spelled out in the bill. Such provisions should make it possible to fill some of the present gaps that exist in service programs for the developmentally disabled, gaps which have diminished the effectiveness of many of the programs because often gains made in one phase of a program are lost when an individual is discharged because he reaches an arbitrary age limit or when he is considered "to have reached the maximum benefit."

For example, many children who have had special education and training and therapy during their school years and who possibly have achieved a reasonable level of functioning, are now adults and are sitting at home with no activity programs, and not even regular medical supervision to maintain the physical gains they have made.

The list of services defined in the bill is more comprehensive than in any previous legislation. However we would like to suggest the addition of just two more. Namely, transportation and follow along service.

Transportation we feel is an essential service element in any program for the disabled. If the individual cannot get to the service, obviously, he cannot benefit from its being available. Many programs are underutilized because transportation is inadequate. We urge, therefore, that transportation be duly considered as one of the important services for which Federal and State funds should be used in a comprehensive program.

Likewise, we have found that many of the developmentally disabled and their families are unable to find their way through the maze of services and agencies available to them without a guiding hand from someone knowledgeable concerning resources.

Many individuals have gotten lost and fallen between the service cracks because no agency felt it was their responsibility to serve as a third parent to the disabled person and his family. Information and referral services, we find, in many communities are not enough. The follow along aspect is vital. Some agency must assume the role of a third parent to insure that the service and the client or his family are brought together at the appropriate time throughout the life of the disabled individual.

Senator DOMINICK. Mr. Messner, why cannot the local communities provide transportation? Why should the Federal Government have to provide local transportation?

Mr. MESSNER. Senator Dominick, I am not suggesting that this be entirely a Federal responsibility. I think that it has to be a partnership as all of these services must be.

Senator DOMINICK. Why?

Mr. MESSNER. Partly because the mass transportation that is now available, particularly in our urban areas, is totally inadequate for the disabled.

I think you are aware that some studies are being done with regard to the use of mass transportation by the disabled and major recommendations are being made for improvement of mass transportation. But without a commitment of a great deal more funds than we see on the horizon at the moment in this field we do not feel that mass transportation is ever going to provide the answer.

This means that if the disabled are going to be able to take advantage of programs that are available, special transporation has to be provided and this can take a variety of forms.

We have had some good experience with volunteer transportation. This, however, is limited by a number of factors. We hope some day the Department of Transportation will take a look at what some of the insurance restrictions are on volunteers transporting disabled people.

What it comes down to finally is that the agency providing the program has to furnish transportation as part of the service program. I think it would be of interest that our affiliate in New York City is budgeted for a quarter of a million dollars for transportation for this year alone. Otherwise, the individuals would not get to the services.

The voluntary funds and the local community funds can provide part of the funding but not all. We would consider transportation as much an essential part of a total comprehensive program as any other aspect.

Senator **Dominick**. I would agree with that. I am not sure I agree with you on the funding of it. But go ahead.

Mr. **Messner**. I would like now to discuss a little more specifically how this bill will help those with cerebral palsy. As I indicated before, cerebral palsy is a general term that applies to a group of disabilities caused by injury to the developing brain. The result is impaired motor function.

However, this is almost always associated with and found in combination with other disabilities. I have indicated perhaps two-thirds of the cerebral palsied are also mentally retarded. About half have speech and communication disorders. A third have visual problems. Twenty percent have hearing difficulties. An undetermined number have learning disorders associated with conceptual and perceptual problems.

So we are dealing with a complex problem. Some individuals with cerebral palsy are only mildly handicapped and require few, if any, services. Others are totally disabled and many of these will be found in institutions for the retarded, whether or not this is the most appropriate placement for them.

In between these extremes there is an infinite variety of combinations of disorders. Most individuals with cerebral palsy do need special srvices and these almost always have to continue throughout their lifetime. These services are costly and certainly no family can afford to pay for all of them; nor can a single health agency provide the whole range of services.

At least 50 different kinds of services are needed at different times and in varying quantity. Not only the individual with cerebral palsy needs help but the families of handicapped also need a variety of supportive services to maintain their stability. UCPA has tried during its 20 years of existence to help meet these needs.

Through 45 State affiliates and 259 local community chapters a wide range of diagnostic treatment and care programs have been provided, supported or purchased.

However, there are gaps in the program. Many individuals with cerebral palsy have not even been identified and referred to existing services. Some of the more severely disabled are residents in institutions. Children and adults in rural areas and in many of the inner-city ghetto areas in many instances do not get to available services.

This is true not only of the cerebral palsied but the mentally retarded as you have heard. Some individuals who have been in specific phases of the program are no longer eligible because of age or degree of disability restrictions.

UCPA continues to face challenges to see that the services are available to meet the physical, psychological, social, and intellectual needs of cerebral palsied children and adults.

To carry out this mission there must be an effective partnership with other services, both public and private. We see the developmental disability bill as having a tremendous potential for helping us meet this challenge.

I would like to highlight three specific areas of program wherein we feel this bill can have particular significance.

First of all: Protective service. Of the approximately 700,000 cerebral palsied in the United States, about 250,000 are estimated to be within the normal range of intelligency. About 33,000 of those are adults so severely handicapped they cannot work even in sheltered workships. They need lifelong help in managing themselves and their affairs. For want of a better term we call these services "protective services." They are generally primarily case management services of a social or a socio-legal nature and they are essential, particularly when there is no longer a family in the picture.

For those who are also mentally retarded these protective services would include public guardianship. We feel that the developmental disabilities bill can help in establishing these kinds of services which for the most part do not exist today.

Second: Developmental day care centers for children. We estimate that there are at least 10,000 children of school age who because of the multiplicity and severity of their disabilities are not being served in public school classes. UCPA has been concentrating some attention on programs for these children during recent years and at present about 3,000 are being served in UCP developmental day care centers.

These programs are time-consuming and costly. We spend about $1,700 per child per year, including transportation, for these programs. You might, however, want to contrast this with the approximately $10,000 per year that it would cost to provide adequate institutional care for these same children.

At this point I think it is appropriate for me to give special endorsement to the hospital improvement and the hospital in-service training programs which we understand will also be authorized under this bill. These programs have made it possible for many improvements to take place within the residential institutions. As one example I cite the involvement of our nurse consultant who has been used quite widely to conduct training programs within the institutions for patient care personnel on how to care for these multiple handicapped, mentally handicapped retarded individuals.

More adequate funding would do much to provide for improvement of such care.

The third category I want to mention is expansion of services for adults who cannot be employed even in sheltered workshops. At this point I would like my associate, Mr. Weinrich, who, as has been indicated, is disabled from cerebral palsy, is a trained social group worker and has been carrying primary responsibility for this phase of our program, to take a few minutes to tell you about this.

Mr. WEINRICH. I appreciate this opportunity to express some of my thoughts about this act and what it could mean to the severely handicapped adult. I emphasize severely handicapped adult. As was indicated, I have cerebral palsy. I am one of the few CP's who got through life without very much specialized service.

I am also one of the few who are working. Because my handicaps are not severe I have been able to take advantage of opportunities that society accords its nonhandicapped members. I have received training and experience as a social worker.

My education and experience is helping me to coordinate a national UCPA task force concerned with promoting service programs for the nonworking teenagers and adults and devising means for their delivery.

In addition, it is my job to interpret the needs and aspirations of disabled persons to those who are not handicapped and to explain why those in the majority should heed the voice of this special minority: I am trying to speak for the severely handicapped. It would be better if they could speak for themselves and given the opportunity they can.

However, I am here to urge in their behalf your support and favorable action on the bill under discussion.

When I was growing up the problem was not only that medical and therapeutic services were unavailable; the problem then was that they really didn't know what to do to help the condition. Now we do. At least, we know a great deal more.

We know that if we can reach disabled children earlier, we can diminish the impact of their handicaps. And we know that those who suffer a combination of moderate to severe mental and physical handicaps require continuing and comprehensive medical, psychological, vocational, social, and recreational services throughout their lives.

The fact is that we know that the multi-handicapped adult, no matter where he lives, is nearly always without adequate medical care and management.

Very often he has not had the benefit of a medical examination or evaluation for years. Most such persons are also devoid of any meaningful social, recreational, or work activity. It is these services that UCPA would like to provide.

I would like to mention here that some of our affiliates have already started some innovative programs. Some of our affiliates have gone into what we call independent living: simple things such as how to make change, how to dress, hygiene matters, how to take care of an apartment. One of our affiliates has established an apartment where severely handicapped cerebral palsied adults actually receive the experience and training of taking care of and living in an apartment as well as being host and hostesses.

Another affiliate has gone into adult education to broaden life experiences. They have become concerned with voting and have learned the routine concerned with absentee ballots so that they can vote.

In another State we have begun to utilize the life experiences of these adults. They have been through it; they know what the score is.

In a rural area we have begun a "Be A Buddy" program so that social development activities can be promoted on an individual basis. This is going to follow the pattern of the Big Brother movement which has been so successful in this country.

In March, we are going to have a national conference on Life Enrichment of the Cerebral and Multiply Handicapped who are culturally and socially deprived. This national conference is being financed largely by SRS.

In Denver our sheltered workshop is indeed serving the severely handicapped. I have never seen so many severely handicapped adults as in our UCPA sheltered workshop in Denver.

UCPA affiliate groups have identified the severely disabled teenager and adult as a top priority target for services. Passage of S. 2846 would provide the essential support that would enable community groups to begin a concentrated effort in this direction intsead of continuing the piecemeal approach they have had to utilize until now.

The greatness of our Nation has shown that we can go to the moon and also address ourselves to the urgent problems of poverty, unemployment, underemployment, education, housing and to the other social and economic problems of minority groups.

Thus, it is consistent and appropriate for our Government to direct the same concern to the problems of another minority group, the severely disabled, the millions of Americans among us who aspire only to be really a part of our society.

Thank you.

(The prepared statement of Mr. Weinrich follows.)

PREPARED STATEMENT OF ERNEST WEINRICH, M.S.W., ASSISTANT DIRECTOR, PROFESSIONAL SERVICES DEPARTMENT, UNITED CEREBRAL PALSEY ASSOCIATIONS, INC.

I am Ernest Weinrich, assistant director, Professional Services Department for the United Cerebral Palsy Associations. I appreciate this opportunity to express to you my thoughts about the Development Disabilities Services and Facilities Construction and Services Act, S. 2846, and what it could mean to the severely handicapped adult.

It is evident that I have, cerebral palsy. But although I am handicapped, I am one of the fortunate—the one C.P. out of seven who can get through life without specialized services. And, I am also one of the 20 percent of the cerebral palsied who is employed.

Because my handicaps are not severe, I have been able to take advantage of opportunities that society accords its nonhandicapped members. I have received training and experience as a social worker.

Now I use my education and experience to coordinate a national UCPA task force concerned with promoting service programs for the non-working teenagers and adults and devising means for their delivery. In addition, it is my job to interpret the needs and aspirations of disabled persons to those who are not handicapped and to explain why those in the majority should heed the voice of this special minority.

Today, I speak for the severely disabled. It would be better if they could speak for themselves, and given the *opportunity* they can. But today I am their spokesman and I am here to urge your support and favorable action on the bill under discussion.

When I was growing up, the problem was not so much that medical and therapeutic services were unavailable. The problem then was that they really didn't know what to do to ameliorate the condition.

But now, in 1969, we do know. We know that if we can reach disabled children early enough, we can significantly diminish the impact of their handicaps.

And we know that those who suffer a combination of moderate to severe mental and physical handicaps require continuing and comprehensive . . . medical, psychological, vocational and recreation . . . services throughout their lives.

The fact is, that we know that the multihandicapped adult, no matter where he lives, is nearly always without medical care and management. He has not had the benefit of a medical examination or evaluation of his condition for years. Most such persons are also devoid of any meaningful social, recreational or work activity.

It is these resources and services UCPA would like to provide. And it is the developmental disabilities bill that could provide immense assistance to groups such as our own who are concerned with hardcore problems of adults with severe multiple handicaps.

UCPA affiliate groups have identified the severely disabled teenager and adult a top-priority target group for services. Passage of S. 2846 would provide the essential support that would enable community groups to begin a concentrated effort in this direction instead of continuing the piecemeal approach they have had to utilize until now.

Our Nation, has recently begun to address itself to the urgent problems of poverty, to unemployment, underemployment, education, housing, and to the other social and economic problems of minority groups. Thus, it is consistent and appropriate for our Government to direct the same concern to the problems of another minority group—the millions of Americans among us who aspire only to be useful members of our society.

Senator KENNEDY. Thank you very much, Mr. Weinrich. You paint a very bleak picture about programs for the severely handicapped adult. Just what are these people doing today?

Mr. WEINRICH. Unfortunately, the picture is almost as bleak as I have painted it. Many of them are at home doing nothing.

We have had some opportunities among our various affiliates to try new approaches. An outstanding one, perhaps, or an unusual one is that one of our affiliates takes severely handicapped adults on trips—here to Washington—as a matter of fact, all over the world.

Another affiliate is concentrating on the practical aspects of living, communication, typing.

The interesting part of this is that most of these programs are not in special facilities but we try to use what facilities are available in the community: community centers, churches. We have homemaking programs, cooking programs, reading, writing, and arithmetic.

You will be amazed, Senator, at how many of our teenagers get through school and can't use what they have learned outside. So we are concentrating on those things which make teenagers and adults able to function in society.

These are some of the things that are going on. We need more of them.

Senator KENNDEY. Thank you. That is very helpful commentary, very helpful testimony.

Mr. Messner. I would be interested in learning your reaction to the statement of the Assistant Secretary for Legislation of HEW, Mr. Black, that we are spending $585 million on mental retardation.

He gave a brief breakdown of that figure in his testimony. What is your sense of priorities as to the way we ought to be spending those funds?

Mr. MESSNER. Senator, I, too, would be interested in seeing a more detailed breakdown of that $585 million because I think we were told that actually only about $20-some million is going through the channels of the Division of Mental Retardation.

Obviously, the mentally retarded and others with developmental disabilities do benefit from some of the programs that Mr. Black referred to.

From our own rather narrow standpoint I would say that our people benefit very little. About the only Federal program that some of the adults Mr. Weinrich is describing benefit from is aid to the permanently and totally disabled.

There are, of course, a number of these individuals who are receiving minimal support through this program. But for the most part these individuals are not eligible for vocational rehabilitation services; they are not getting the benefit of many of the educational funds that undoubtedly are included.

The revisions that will be made in the welfare program hopefully will help. But I find it hard to see the $585 million.

I would like to say one thing further in this connection, I think. Mr. Black did indicate that the broadening of the language used in the bill would result in duplication with other services. That may be true in some categories. I am not very familiar, for example, with what is being done through the comprehensive mental health centers in various communities.

He did mention the emotionally disturbed and mentally ill. Certainly from the standpoint of the cerebral palsied, whether or not they are mentally retarded, I can see very little possibility of duplication.

For example, services to crippled children were mentioned. It is true that many individuals with cerebral palsy have been benefited by services to crippled children but for the most part this has dealt only with the motor aspects of their disability.

Also, these services cut off at age 21, so that again the adults who are not eligible for vocational rehabilitation services cannot benefit here.

Again, I see very little possibility of duplicating other Federal and State programs.

Senator **Kennedy**. In terms of the figures that are used in the pending legislation, which are based on our information of the existing need, I wonder whether you would give us your reaction as to whether they are too high or too low?

Mr. **Messner**. You are talking about the figures on incidence?

Senator **Kennedy**. The authorization figures. As a professional concerned with this problem and aware of the dimensions and intent of the legislation, can you give us your reaction to these figures?

Mr. **Messner**. I would say offhand that they seem minimal to do the many, many things that have been identified here. As we listened, for example, to the people involved with the university-affiliated facilities, I would expect that the entire $100 million the first year could be utilized in that direction.

We certainly know that there are great unmet needs in terms of facilities and not residential facilities for the developmentally disabled.

Mr. Weinrich mentioned the fact that we use a variety of community facilities. This has some beneficial aspects but it also constitutes a problem in many respects because of architectural barriers, because of conflict with other groups who need to use these same facilities.

While we would be happy if the bill could be funded up to the amounts indicated, I would say it would only be a beginning.

Senator **Kennedy**. Dr. Helsel, I know you are a geneticist. I wonder if you can give us any information on the progress which has been made in the field of research in this area?

Dr. **Helsel**. In cerebral palsy, not much because it does not seem to have a genetic base. In the field of mental retardation we are making tremendous strides in this area.

However, I think I could contribute to our discussion here not so much as a geneticist but as a parent. As I sat here this morning I realized from personal experience what this fragmentation of diagnostic labeling can do.

We have a 23-year-old son who is very mildly mentally retarded but severely disabled physically. Early in our lives before psychological tests were too accurate, it was decided that he was moderately mentally retarded. He was placed in a community class for the mentally retarded, was doing very well, was happily adjusting, and making good progress.

Unfortunately when review time came along they changed the diagnostic label and said, "No, he is not mentally retarded. You will have to put him elsewhere. He really belongs in a public school. He was transferred.

The public schools were not staffed or equipped to handle him. It was a very disastrous experience for us.

I think this is the kind of experience that can occur in a community in a service area when you have to have the right label in order to fit into a particular program.

Mr. **Messner**. May I suggest, Senator Kennedy, that in the broader area of the research it would seem to me obviously there is still a great deal that we don't know about the causes of cerebral palsy and mental retardation and other development disabilities.

However, I would submit that we know a lot more than we are using. It would seem to me that one of the impacts of this bill would be to put into use some of the research knowledge that has been gained and is not being used at the present time.

Senator **Kennedy**. I want to thank you all very much for coming. It has been very helpful testimony.

Mr. **Messner**. Thank you.

Senator **Kennedy**. It will be very useful to the committee.

Our final witness this morning will be the Reverend Damien O'Shea of Westville Grove, N.J. Father Damien has a special interest in the development of private facilities for the retarded. He is the director of the St. John of God community services in Westville Grove, N.J. Among his principal activities has been the development of a special school program for training mentally retarded children between the ages of 3 and 14.

Father O'Shea, we welcome you before the committee. You have a statement. We can proceed in whatever way is most appropriate for you. You may read your statement if you wish, or you may summarize it for the committee and include the entire statement in the record of the hearings.

STATEMENT OF REV. DAMIEN O'SHEA, O.H., DIRECTOR, ST. JOHN O.H., DIRECTOR, ST. JOHN OF GOD COMMUNITY SERVICES, WESTVILLE GROVE, N.J.; ACCOMPANIED BY LAWRENCE FIEDELMAN

Father O'SHEA. I would like to highlight some of the points of my statement, presenting them from a different angle and commenting on parts of previous testimony submitted this morning.

Senator KENNEDY. Your statement will be included in the record. You may proceed.

(The prepared statement of Reverend O'Shea follows:)

PREPARED STATEMENT BY REV. DAMIEN O'SHEA, O.H., DIRECTOR, ST. JOHN OF GOD COMMUNITY SERVICES, WESTVILLE GROVE, N.J.

Fr. D. O'Shea is particularly concerned with the plight of parents of mentally retarded children requiring residential care who have no choice in the placement of these offspring due to existing legislation and their inability to pay the total cost of private residential care. It is his view that the position outlined in the paper, "The Free Choice Principle in Care of the Mentally Retarded" by Dr. Robert E. Cooke, John Hopkins University School of Medicine, should be adopted and incorporated into the above Act.

"My severely retarded child has been on the State residential waiting list for the past three years and there is still no word about a vacancy."

"I visited my boy in a State residential center and came away on the verge of a mental breakdown after seeing the overcrowded conditions, the dilapidated buildings, the absence of qualified staff, the lack of organized educational and recreational programs and the general air of apathy and surrender to the inevitability of prevailing conditions."

"I can't afford to send my child to a private place and it breaks my heart to see her as a mere forgotten number in the wilderness of nonentities merely existing in a large State institution."

"My child was in a lovely private place due to the State purchasing care there. Now he has been taken out and is in a huge State institution. He is lost there and I'm so depressed that this had to happen."

"I was advised that the quickest way of getting my boy who is mongoloid into an institution for the retarded, was to have him placed in the local State mental hospital. Now he is in there with old senile people for the past two years and I can't get him transferred despite all my efforts."

These are but a few of many hundreds of similar stories coming to our one agency here. Multiplying them a hundredfold or a thousandfold would not exhaust similar human stories experienced in American daily lives.

Is there an answer to this dilemma? Can we walk on the moon and aim at exploring other more distant planets and with our vast technological, scientific and financial resources, are we, who represent the greatest nation on earth, prepared to admit defeat in the challenge that mental retardation poses to us?

The implementation of Bill S. 2846 cited as the "Developmental Disabilities Services and Facilities Construction Act of 1969" would be a very positive step in the acceptance of this challenge.

"The mentally retarded may be the victims of fate, let them not be the victims of our neglect. In all the fields of medical science there is no problem about which ignorance is greater than the problem of mental retardation. It affects the children of the rich and the poor, it transcends geographic boundaries, it does not respect race, color or creed. It is the greatest national, social, cultural and educational problem in the country today."—John F. Kennedy.

The number of retarded is more than double the combined figures of cerebral palsy, poliomyelitis and rheumatic heart conditions.

There are 5,500,000 retarded in the United States. Over 200,000 alone in New Jersey. Facilities for approximately 20,000 in New Jersey; three out of every 100 babies born who are mentally retarded.

About 200,000 adults and children currently reside in 150 public or State institutions for the retarded in the U.S. at a cost of $500,000,000 a year in operating expense alone. This averages out at $7.00 per day per child which is about one-eighth the amount spent for a day's general hospital care. Four states spent less than $4.00 per day in 1966. In contrast five of the largest zoos a few years ago were spending an average of $7.00 for their large animals.

Another 20,000 retarded reside in approximately 500 known private facilities. Many thousands lie in mental institutions or approximately 10% of all residents in public mental hospitals are retarded.

Over half the public institutions in this country house more than 1,000 residents per institution.

A triple problem confronts most public residential facilities: (1) *Overcrowding*, (2) *Understaffing* and (3) *Under-financing*.

(1) *Overcrowding*: Many institutions have a three year waiting list or longer. Most institutions—already overcrowded—would have to expand by more than 25 per cent in order to eliminate their *current* waiting lists. Even if this could be accomplished what about the more than 3,000 who are annually added to the numbers requiring residential care.

(2) *Understaffing*: About 11% of the 90,000 persons employed in public institutions are classified as professionals. Most of these are teachers and nurses. The nurses are usually State registered nurses with little professional training in the field of mental retardation. Fewer than 2% of all institutional personnel are classified as psychiatrists, psychologists, social workers and speech therapists. Attendants are the main executors of institutional programs with responsibilities ranging from being a substitute parent, janitor, record-keeper, part nurse, part physical therapist, part psychologist and part educator. Though they are the most important people in the lives of the institutionalized retarded, the vast majority come with no relevant past experience. Many come with less than a twelve grade education. A recent survey showed that in 16 States on the average, 20% of the attendants are replaced in a year. The high turnover is due to the undoubtedly low standard and criteria of selection and the scarcely above poverty salary scale they receive. Most attendants earn less than $350. per month. Many earn far less.

(3) *Underfinancing*: The 1966–67 per diem costs over the country (excepting Alaska which is $22.00) range from $3.00—$4.00. This contributes to the understaffing in relation to professional and non-professional persons. In many states professional salaries have been so low as to attract no one of competence and non-professional salaries for attendants in many areas are frequently below the national poverty level. As a result in 1967 about 30% of all budgeted positions in public residential facilities are now vacant.

Adding to this bleak picture may be included the following defective points which equally merit chapters to themselves—

(*a*) Obsolete architectural and philosophical design of most institutions;

(*b*) Remoteness of institutions from urban settings;

(*c*) Lack of a greater educational program for a generally unenlightened community;

(*d*) Inertia, despondency and frustration by administrators and politicians in not accepting the problem as a challenge and thereby ensuring retarded persons their constitutional and inalienable rights;

(*e*) Inability of the retarded to speak for themselves and too few with the time or desire to champion this supposedly lost cause;

(*f*) Blindly seeing the retarded as numbers, statistics and classifications rather than as individual human beings and seeing their parents as persons who could have been YOU or myself;

(*g*) Equating the retarded person with a dollar and finding the dollar the winner;

(*h*) Just as the Medicine Act of 1965 applies to so many health services, is not the residential retarded person and parents entitled to a counterpart service?;

(*i*) Shall the low and middle income group of parents be continued to be deprived of their earned rights and prerogatives in seeking after what is better if not best for their retarded offspring in need of residential care;

(*j*) The previously dogmatic statement that the large institution of a 1,000 beds or more can be operated more economically than the small personalized center of 50, 100, 150, or 200 beds, is already under siege as a fallacy and rightly so;

(*k*) Surely it must be possible for us to profit from our own mistakes and from the experience of others more qualified in the field especially in relation to the philosophy and methodology of the implementation of modern and futuristic residential programs in Europe.

May I briefly be permitted to give a resume of a program instituted by the Brothers of St. John of God since arrival in the United States four years ago. This program up to the present has been underwritten and sponsored by the Diocese of Camden, New Jersey. While it is a private day school program rather than a residential one, it conveys many progressive ideas and features that could be equally applied and incorporated into a residential private program as is advocated here. It portrays a progressive and optimistic outlook, avails of the most up-to-date means and materials and utilizes the seemingly infinite availability of *volunteers* comprising doctors, psychologists, university professors and lecturers, nurses, carpenters, plumbers, electricians, gardeners, typists, accountants, university and high school students, housewives and a host of other persons qualified in a varying multiplicity of areas. Perhaps their involvement has been stimulated by their recognition of how little is being done in the total field of mental retardation, the vast amount that *can* be accomplished and allied to the fact that the Brothers have the professional and practical experience of thirty years' study and involvement in residential and day programs in Ireland, England, Scotland, the Netherlands and Scandinavia.

A. *Type of Program:* Special day school for 90 trainable retarded pupils aged 3–14 years open to children of all denominations and tuition free. Over 70% of the pupils have Down's Syndrome (Mongoloidism).

(1.) *Special Features of School:* It is located on a 27 acre site allowing plenty of room for expansion. Between the eight classrooms and cafeteria, gymatorium and offices there are no steps. Ramps are utilized in order to facilitate pupils with physical mobility problems and thereby allowing for the multi-handicapped child. All classrooms are carpeted, larger than State requirements, the maximum of light is used. Each classroom is completely self-contained equipmentwise with plenty of closet space. Trapezoid and semi-circular tables, chairs, sliding blackboards, visual aids are also adjusted to the height of the pupils within the different classrooms. Off each classroom is a smaller room allowing for individualized instruction, as for instance speech therapy. Toilets, baths and showers are adjusted to the pupils' size. A unique feature is the installation of one way mirrors off every classroom allowing for observation by parents, students and visitors and permitting tuning into classroom programs and taking of notes without children being aware of observers. Also included is a fully equipped home economics unit permitting cooking, table setting, clothes washing and drying, sewing, bed making, hygiene and hair styling. Two indoor and outdoor play areas including a large gymatorium are added features as well as a conference library room, production center unit and a medical health suite.

(2.) An academic-occupational-social program is stimulated from the earliest years. Exposure to outside influences including ice skating, bowling, trips to zoo, pony farm, museum and recreational centers are used to stimulate emotional, maturational and social development. In each classroom, in addition to the trained teacher there may be one, two or three volunteers. Some of these are retired teachers, music or art instructors or housewives with patience, understanding, love and discipline. Sixty mothers of pupils operate on a rotational basis in assisting the children at mealtime. Monthly educational meetings of parents and friends are added to a regular classroom monthly meeting where the school and the home is integrated into a joint approach toward benefiting the pupil.

B. *Medical Health Program:* This includes 20 medical doctors of different specialties and 20 nurses who have volunteered in providing a comprehensive medical health and sex education program for the pupils. The medical information obtained is designed in such a manner that it can be computerized at a later stage with a view to medical research into some of the causes of mental retardation. The medical health program includes liaison and participation where possible with hospitals, universities and research centers engaged in the field. An additional objective of the medical health program is to notify maternity units of general hospitals so that the parents of newly born retarded children may be informed of the program including our special pre-school program.

C. *Pre-School Program:* (Saturady morning session) At present 36 children ranging in age from 3 weeks to 3 years participate in this program. This mainly consists in stimulation of the child emphasizing the over riding importance of early education as soon as possible. A specific program covering motor, sensory, speech and social areas is designed for each child and implemented by an individual counselor for each child. These *volunteer counselors* are mainly high school and college students and the criteria include faithful regularity in attendance, patience, understanding, adaptability, orginality and flexibility. Operating simultaneously with this section, is a group counseling program for the parents of these children utilizing doctors, psychologists, teachers, clergymen of all denominations and making available to them current helpful literature and demonstrating equipment and techniques that can be used at home to supplement the efforts of the counselors. A particular function is also to make them aware of how to have their special children registered with the State. Should institutionalization ever arise, the various private and public pre-school programs available and how and when to go about applying for admission to such programs.

D. *Vocational Habilitation Program:* For pupils aged 15 years and upwards. This is still in its embryonic stage where we have a number of business and professional people instituting fund raising projects for a unit which will cost $500,000 and also an endowment fund to ensure its operation.

E. *Private Residential Program:* For approximately 100–150 severely retarded residents. This at present is a dream but may be rendered feasible and possible if the free choice principle for parents is approved and implemented. Like others who dream a dream we also echo those immortal words:

"Some people look at things and ask themselves, why, Others look at things that have never been and ask themselves WHY NOT."

REASONS FOR CONSIDERATION OF PASSAGE OF BILL S. 2846 (91ST. CONG., FIRST SESS.) ESPECIALLY IN RELATION TO SECTION 130(b).

In a spirit of optimism and faith in the intrinsic goodness and honesty of the legislators of the most wonderful country of the world where life, liberty and the pursuit of happiness is ingrained into the very fibre of the United States, I shall now attempt to translate some of the ideas already expressed into some valid reasons why the principle of free choice should be granted to parents whereby they may have a choice of residential centers for their retarded children needing such care and always allowing for adequate medical reasons justifying such a placement.

(1) More or renovated State institutions will never supply the answer to the ever increasing needs for residential care;

(2) Large institutions are demoralizing in their impersonal nature.

(3) Increse of private non-profit residential centers and licensing conditions of operation will increase the standard of efficiency and care both at private and State institutional levels;

(4) Greater flexibility can be excerised by a private non-profit residential center in relation to its proximity to an urban area, training and placement of pupils in employment or sheltered workshops and utilizing the concepts of the foster home, the hostel and half-way home.

(5) Small purpose residences can be developed to specialize in certain areas i.e. educable or trainable retarded who may need residential care because of family circumstances and yet are capable of limited work within the community; unit specializing in the multi-handicapped resident; child development center; general medical care unit; non medical special purpose unit.

(6) Association with university or research center may be rendered more feasible through construction of local small private centers and, also facilitate the training of personnel.

(7) A wide array of residential services needs to be devised if retarded persons are to have quality care and treatment—this necessitates the establishment of more non-profit private centers with high standards subject to inspection periodically and subsidized by State or Federal funds;

(8) The vast potential and availability of volunteers qualified in medical, para-medical and non medical areas is much more feasible and practical within the framework of a private non-profit residential center and assumes a more comprehensive service at an astronomically lesser cost than an equivalent State residential service. This already has been demonstrated in the educational program operated by the Brothers of St. John of God in contradistinction to a local public education board subsidized by the State.

CONCLUSION

The areas of mental retardation are so diverse, the needs are so great in providing an adequate service that every avenue should be pursued including grants to assist public and private *non-profit* agencies in the construction and operation of facilities for the provision of services to those persons affected by developmental disabilities. In providing such a comprehensive program the constitutional rights of parents and their retarded children are best ensured. Therefore the passage, approval and implementation of the Bill, S. 2846 incorporating the principle of free choice of residential centers by parents and approved by competent medical authority is hereby advocated.

Father O'SHEA. Senator, thank you for allowing me the privilege of being here. The gentleman on my left is Mr. Lawrence Fiedelman, a parent of a 2-year-old mentally retarded child who suffers from Downs syndrome.

As a representative of a private nonprofit, nonsectarian program for retarded persons I have come to advocate the passage and implementation of this bill entitled "Developmental Disabilities Services and Facilities Construction Act of 1969," not only in relation to subsection (a) of section 130 but particularly with reference to subsection (b) of section 130 which states:

> The purpose of this part is to make grants to assist public and nonprofit agencies in the construction of facilities for provision of services to persons affected by developmental disability.

The program which I represent, St. John of God Community Services, diocese of Camden, N.J., contains these characteristics in being private, nonprofit and it is also nonsectarian and in addition, it is a tuition-free program.

The only criterion for admission to our program is that the pupil is mentally retarded, that he may benefit from our services, and that a vacancy exists.

Personally, I do not feel that a purely sectarian private program should benefit by this act.

The role of the private nondenominational, nonprofit agency is not to supplant or compete with Federal, State, or local authority programs but, rather, that it should supplement them in the provision of services that are either totally lacking or very inadequate in content.

This act stresses the development or implementing of a comprehensive and continuing plan for meeting the current and future needs and facilities for the provision of services to persons affected by developmental disabilities.

First, I realize, and it was brought out here this morning, that developmental disabilities do not confine themselves to mental retardation. Nevertheless, it is with reference to this aspect I am here concerned. As indicated in my submitted statement, mental retardation is a multifaceted kaleidoscopic condition calling for a conglomeration of interdisciplinary approaches to help alleviate it.

A different level already mentioned this morning was prenatal care, family planning. Certainly these are to be considered and the more research into these areas, the better. But we are actually faced with children here and now. Since this morning many retarded children have been born. We are faced with infants, preschool children, schoolchildren, children at a vocational level, children who are retarded persons in need of placement and retarded in need of residential care.

I believe the answer does not lie in State or private institutionalization or residential care. The majority of retarded can, with education and training, be fully or partially integrated into the community and this must be our objective, utilizing the most modern and futuristic means of rendering this possible.

Though I describe it in my written statement, may I highlight a few aspects of the school program operated by St. John of God Community Services?

It is a school for trainable retarded children with an IQ of 35 to 50. Seventy-five percent of these children are mongoloid children. They range in age from 3 to 14 years.

May I answer why did we start this school for trainable retarded children? We came over from Ireland where we specialize in this field where we cared for over 2,000 children. We felt that the outlook over here was quite favorable with respect to the educable retarded child but very backward in relation to the trainable and the types of programs available for them.

Many of these programs are merely babysitting custodial types of programs. We feel that the potential of trainable children is not fully realized. For this reason we have concentrated on this type of child, the trainable retarded child.

Our school designed for 90 to 100 children cost $500,000. We did not receive 1 cent of State or Federal aid. The money was raised by the diocese of Camden through subscriptions by people of all denominations since the program is open to children of all denominations.

It has special peculiar advanced characteristics. The physical characteristics: All the classrooms are larger than the State requirement. The classrooms are on a completely different level to the gymatorium, the cafeteria, the offices, yet there are no steps in the school. Instead of steps we have ramps so that if at some future stage we have classes for the physically handicapped who are also retarded we would have no problem within our school to accommodate such children. Each classroom is completely self-contained.

We do not have to borrow equipment from a central storeroom. Visual aids are in each classroom. There is plenty of closet space. Every room is carpeted which is good in the education of these children, doing away with the noise problem.

We have a small room off each class where we can do individual work with the child, such as speech therapy. Also, off every classroom is a one-way mirror where parents who are concerned about how their children do at school can observe their children, where visitors can observe our students without disturbing the activities within the classroom.

All the furniture is designed for the height level of the children. The toilets are equally designed. And it has a special home economics unit which presents unique features in helping these children at home.

Our program is an occupational-educational-social type of program.

We believe in exposing these children as much as possible to the community. We believe in the value of things like ice skating and bowling as a means of developing their coordination and also of developing their social lives.

Our children come from 36 different townships. In fact, one child, a 4-year-old child, travels 54 miles to our school every day and 54 miles home. The transportation is provided by our Parents and Friends Association.

Last year it cost us $15,000 to contract with a bus transportation company for our children. This year we have bought two buses, hired two drivers, two monitors. The total cost is provided by the activities of our Parents and Friends Association.

A particular feature of our school is the use and introduction of volunteers. In every classroom as well as having a teacher we may have one, two, three, or four volunteers. Some of these may be retired schoolteachers, nurses, music instructors, arts and crafts instructors, but basically the majority of them are parents, not parents of our retarded children but parents who wish to help in some way, giving perhaps 1 day a week to our program to the same class.

Some volunteers may give 3 days a week. Basically we would like to give them 1 day a week to the same program. In this way we can concentrate on each individual child who is in that class so that the progress of the whole class is not held up by the backwardness of two or three children. The volunteers receive no pay.

For some subjects all the children come together. For other subjects they are broken down into small groups and it is here the volunteers prove their effectiveness.

In addition, we have a voluntary medical health program for our school. Again, I think this is pretty unique. We have at least 20 doctors and 20 nurses on a voluntary basis who are supplying a medical help program to our school. The program they are supplying I would consider to be one of the finest in the country.

Again, it does not cost anybody a penny. Also, among our parents and friends we have additional volunteers, carpenters, plumbers, electricians, painters, gardeners, typists, bricklayers, high school and college students. We utilize high school and college students very much and in this way we are getting more and more of them interested in perhaps pursuing careers in special education or in the nursing of retarded children.

Every month we have a monthly parents and friends meeting where we have a gifted speaker and in addition we discuss some projects to help our school.

Also, in addition, we have classroom meetings where the parents meet with the teacher of that class and discuss what is being done and how the parents can complement it at home.

We are as concerned about what the parents do with the children for the 19 hours they have them at home as the parents should be concerned with what we are doing with the children during the 5 hours we have them at school. So we want to integrate the two approaches.

We can also discuss things like birthdays, whether they will be celebrated in the classroom, whether we will take them to the animal farm, to the circus, to the zoo or other places.

It involves the cooperation of parents acting as chaperones for these educational and social outings.

Our school is full of what I may call "statues" but these are not wooden statues like you see in churches. People ring us up occasionally and they want to give us something in memory of somebody who has died. It may be a husband, it may be a wife, it may be an active member of some association. Usually they say, "We would like to give a statue." I say, "Fine. How much would you like to spend, $10, $15, $50, or $100," sometimes going up to $500.

"Fine, we can get a lovely statue life-sized hand-carved before which the kids could say their prayers."

But do you not think it would be a dust catcher? Would it not be of greater benefit to give us some equipment to help the children?

So in this way, we have overhead projectors, pianos, tractors, equipment for the kitchen, photostatic machines, typewriters, and so forth. To use these are much more important and they contribute very much to the education of the children and also are a help to the teachers.

I mentioned earlier that this comprehensive approach must also be supplied to the infant and preschool retarded child. If such emphasis is placed on early education today, why must a retarded child have to wait until he or she is 5 or 6 years of age before being received into a State educational system?

Why must the parents of such children undergo the anguish of these years in seeking and more oftentimes failing to find resources that might help them in the motor area, sensory area, speech, social and other maturational areas that are so underdeveloped in these children?

I believe that a factor that contributes to the incidence in residential institutions is one where the parents despairing of any hope of help eventually must have recourse to institutionalizing their child, something the parents do not wish to do, something that is not best for the child, something that is increasing the citizens' taxes, something that is unnecessary and a burden for the State.

A minimal but meagre answer is the role played by private, nonprofit and nonsectarian agencies. Here again, I must confine myself to a few points elaborated upon in my written statement concerning our preschool program.

As already mentioned, our regular school program is for children age 3 to 14 but we have a preschool program; it operates 1 day a week on Saturday. It is for children aged 3 weeks up to 3 years. In fact, last Saturday we admitted a child 2 weeks old to our preschool program.

In this program we have a counsellor for each child and a special program designed for each child. Most of the counsellors are high school girls, college students and some older people.

In reference to this, what can you do with a child so young? We believe the answers can be found. In this instance I visited a very large, very renowned children's hospital in Philadelphia, thinking I might find the answers to some of our questions. Questions like what are the different stages of development in the motor area, sensory area, speech area, the social area of children?

What level should be a child be at 4 weeks, 8 weeks, 12 weeks? What are the next steps in the different areas?

Are we overlooking a step that is of vital importance?

I was told some of these questions which I was asking were questions that this hospital specializing in children's care would not be asking for another 10 years. Instead of receiving help from them they are in the process of coming out next week to study our program.

But in addition to this program for the children, with a counselor for each child, we also simultaneously operate a counseling program for the parent, again utilizing doctors, nurses, social workers, administrators, persons from the local and State agencies, clergymen of all denominations and also using films, audiovisual means, and making available to them any literature that can be of help to them, literature which they cannot get hold of themselves.

And basically, if parents receive counseling at this early age they will not be faced with the many problems that will arise in later years.

To me this is the most essential part of this preschool program.

Just 3 weeks ago, a famous surgeon in Philadelphia had a mongoloid child. He was advised by a physician to put the child in an institution because nothing could be offered at this particular stage. He heard about our program, his child is now in it. Now he is very much involved and intends to keep his child at home.

Senator **Kennedy**. Father, please excuse me. I don't wish to interrupt you, but I am running into a problem with the time schedule. Your full testimony will be included in the record.

If you would perhaps summarize the rest of your testimony I would like to ask a few questions, and then I am afraid I must go to the Senate floor.

Father **O'Shea**. Thank you, I shall summarize the rest.

Again, in reference to the school program, I believe much can be done at the vocational level in strengthening the children's vocational programs from the age of 15 since most programs are totally inadequate in this area today.

As a result of doing this, it would also prevent many of these young adult retarded ending up in institutions. I did mention in our report that a small percentage require residential care. Even this the State cannot adequately provide as pointed out in the statement. Institutions are overcrowded, underfinanced, and have inadequate staffing. Archaic and dilapidated buildings abound.

May I again state that the role of the private nonprofit, nondenominational residential center is to supplement and complement the tremendous but very inadequate State residential program.

I do believe, however, that the act is defective in this respect in that it does not allow the freedom of choice to parents subject to medical prognosis in the placement of their retarded children actually requiring residential care.

My written statement elaborates on this point and offers a solution in accepting the principles outlined in Robert E. Cooke's article entitled "The Free Choice Principle in the Care of the Mentally Retarded."

Apart from this point the act receives my unqualified approval and I ardently support its passage and implementation.

Senator **Kennedy**. Thank you very much, Father. You have given us an excellent insight into the program in which you are so deeply involved in New Jersey.

I must say that the program is extremely imaginative. It appears to utilize every bit of local initiative, voluntarism, energies and ideas that one can possibly imagine. You are to be commended for the leadership you have provided, and the people in the community are to be commended for their interest and their support.

I would like to ask you about your relationship with the State agency in New Jersey. Are you in touch with them? Are they in touch with you? Do you have any kind of communication or exchange?

Father **O'Shea**. Yes, I have been in touch with the State education and department of institutions and agencies and there is a very cordial understanding between us but, again, there are barriers, reasons why they cannot assist us because there are so many demands at State and local authority level that they must answer to before looking to the needs of private centers like ours.

Senator **Kennedy**. Of course, they include your effort in the total planning program for the State, do they not?

Father O'Shea. They are aware of it, they would like to include it. But oftentimes it is not a question of including it. Sometimes the programs outside might be very inadequate. We might supply a program that is better but the very fact that a program is being supplied at a local authority level is sufficient as far as they are concerned. For example, the question of residential care has been brought up here. Many parents have come to us, whose children have been on the waiting list for the past 3 years.

I know one recently where it was suggested by a Senator to parents that the best way of getting their child into an institution for the retarded was to admit him to a State mental hospital. This child was admitted to our State mental hospital and it has taken 2 years to get him out of there into a State institution for retarded children.

Again, we have waiting lists, the State has a waiting list for State residential centers.

It also had a standby waiting list for parents who did not wish their children to go into an institution at this stage but perhaps later as they grew older. But the standby waiting list has been done away with. The parent's child only goes on the waiting list when he or she feels their child needs residential care and then this process of waiting 1, 2, 3 years starts.

Senator Kennedy. Do you wish to make any comments, Mr. Fiedelman?

Mr. Fiedelman. The only comment I do want to make is that this type of program does give a parent hope and without it I feel that most parents would have to eventually send their children to institutions which does not make anything good for the family or the State.

I feel that the way out is to build up the educational facilities and then we won't have to worry so much about our institutions.

Senator Kennedy. I want to thank you both very much for your appearance here and for your comments. They will be very useful to the members of the committee. It is a very exciting program, and I am grateful for your appearance.

During the course of the testimony by the administration witneses, we received some helpful comments from Miss Doris Fraser on the status of mental retardation programs in Massachusetts. Also with us this morning is Mr. John F. O'Leary, the special counsel for health affairs to Governor Sargent in the State. Mr. O'Leary had prepared a statement on S. 2846 on behalf of Governor Sargent, and I had hoped that Mr. O'Leary would be able to present the testimony this morning. Unfortunately, because of our other commitments, the subcommittee must now recess, but Mr. O'Leary has agreed to submit his prepared statement for the record of these hearings, and I ask that it be printed at this point.

(Mr. O'Leary's prepared statement follows:)

PREPARED STATEMENT OF JOHN F. O'LEARY, SPECIAL COUNSEL FOR FRANCIS W. SARGENT, GOVERNOR, COMMONWEALTH OF MASSACHUSETTS

Mr. Chairman, Francis W. Sargent, Governor of the Commonwealth of Massachusetts, has requested that I appear today in order to present his views on this bill. I am John F. O'Leary, Special Counsel for Health Affairs to the Governor.

Governor Sargent firmly supports the intent of S. 2846, "Developmental Disabilities Services and Facilities Construction Act of 1969." It fills major gaps currently existing in federal legislation through the new provisions which assure the state the essential elements of continuing planning and inter-agency program development support. The bill is laudable to the extent that it ties together federal, state, local, public, and private agencies in a more integrated approach to the delivery of essential human services for persons with developmental disabilities.

TITLE AND PURPOSE

Title I—Section 130 (page 2)

The title and purpose of this bill resolve the problem of stigma and narrow categorization of persons by disability, yet protect those, who, by reason of existing law, are now identified by category. The bill's major contribution is the term "developmental disabilities" which clearly provides for multiply handicapped children and adults. Many youngsters who are now the recipients of several labels by reason of their diverse handicaps, such as the blind, retarded, epileptic, emotional disturbed child are not eligible for programs by reason of statutory constraints at the Federal and State levels. Fragmented service, or no service has unfortunately been the rule rather than the exception for the multiply handicapped. The proposed title and purpose will provide new intiative to parents and practitioners to view the handicapped person in more unified terms for both program development and administration. Fragmentation of services for persons who are primarily physically handicapped yet function as retarded through faulty social adaptation are fortunately included in the new definition of "developmental disabilities." While this bill protects the high priority needs of retarded persons, it also provides the states with sufficient latitude to include a variety of developmental disabilities in its state plan according to individual state structure and needs.

The comprehensive nature of this bill, both in definition and administrative scope, reinforces reorganization efforts now underway in Massachusetts to modernize public administrative structures in dealing with multiply disabled persons. An essential part of the modernization of state government in Massachusetts is the development of an integrated administrative and service delivery system for the field of human services. Senate 2846 is consistent with the current plans and activities in Massachusetts. Massachusetts has recognized the need for formal planning and program coordination for the field of retardation and other handicapping conditions at the executive level of government. Within the Office of Planning and Program Coordination, at the executive level, we have a Bureau of Retardation which coordinates the efforts of twelve state agencies for the multiply handicapped retarded. We believe this Bureau to be the first of its kind in the nation and it signifies Massachusett's commitment to planning as an essential prerequisite to the delivery of comprehensive care for multiply disabled people.

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We appreciate and support the flexibility given to the states in those provisions which allow the state to determine the administrative structure for program coordination and planning. The provision for continuing planning allocations is long overdue. Recognizing that the nation is spending over 14 billion on health care alone, with less than 3.4 million being spent on planning and program evaluation, suggests that we should strongly support the sections which would provide for block allocations to states to assure on-going planning capability, program development, and needed construction. Continuing to pour money into traditional fragmented approaches, without support for continual reassessment, will not allow for the development—through alternative approaches to resource allocation—of new and more effective solutions to the problems of our severely retarded and disabled.

With your indulgence, Mr. Chairman, I have some recommendations which would modify the proposed provisions and some suggestions for new provisions.

STATE PLANS

First **(pages 7 and 8)**

S. 2846 should specify in an amendment to Title I, Section 134 that the state authority designated to carry out the planning and supervision of the state plan will have ultimate responsibility and approval power over the participation of public and private agencies who apply for participation in the state plan.

Section 134(B)(2) should state that the role of the state agency should include the power to approve individual, public and private agency application for

funds through this legislation and that their eligibility to receive funds is contingent on their applications being consistent with the objectives and priorities of the state plan.

We have found through experience in Massachusetts that an applicant who is eligible to participate in many federal programs can circumvent state plans because of the lack of approval power in any single state agency to assure consistency with federally required state plans. The recommended new provisions would be consistent with the new measures in the Intergovernmental Cooperation Act of 1968 which requires state and regional review of grant applications.

STATE ALLOTMENTS

Second (page 3)

Section 132(a)(1)—Criteria for Determining State Allotment (A, B, C)

Massachusetts is firmly committed to the use of the criterion of "*Extent of Need*" in determining the level of a state's allocation, as well as the criteria of population (A) and financial need (C).

A general problem the state of Massachusetts finds in many federal programs is, that the reimbursement formulae penalize rather than reward those states that have expended great resources, and have built up a momentum and expectation for service. To the extent that Massachusetts is essentially industrial, urban, and densely populated, it is essential that our unfinished business—the elimination of pockets of extreme social deprivation—be given consideration in determining the scope of federal criteria for documenting a state's need. We would hope that the regulations take into account the continuing urbanization and the concomitant problems it brings for service delivery. Most of our disabled people live in densely populated sections of the central city, or in large state institutions which all too often may be the remnant slums of former generations.

PAYMENTS TO THE STATES FOR PLANNING AND SERVICES

Third (*page 17*)

Section 137(b)

The inclusion of the private sector in determining the level of state expenditures is a laudable public policy development. This provision will enable the federal and state governments to have a more realistic appraisal of the actual expenditures and benefits derived from both public and private investment policies for developmental disabilities.

The bill should, however, specifically permit a non-public applicant, who has been approved, to be a direct recipient of such federal funds. Such a provision would be vital for us in Massachusetts because of a restriction in our state constitution which prevents the allocation of public funds to private agencies.

CONSTRUCTION, DEMONSTRATION, AND TRAINING GRANTS FOR UNIVERSITY-AFFILIATED MENTAL RETARDTION FACILITIES

Title II—Section 201 (p. 22 of bill)

We applaud the broadening of the training base in Section 202 from "clinical" to "interdisciplinary training." The major thrust in manpower development in the next decades must reflect our recognition that the physically and mentally disabled require training, prevocational and vocational skills, and new educational approaches in close collaboration with the clinician. However, we will attract and hold a manpower pool capable of meeting the range of service needs of handicapped people to the extent that we involve the college student who is committed to human services training, as a meaningful member of the interdisciplinary training team.

MAINTENANCE OF EFFORT

(*Page 25*)

We strongly recommend that Section 126 should include a provision that the Secretary consult the state planning authority prior to approving any grants under Title II in order to assure that such applications are not inconsistent with obligations and commitments in the state plan.

On behalf of the many interested public and private organizations in the Commonwealth, I thank you for this opportunity to share with you the concerns and hopes of the Governor for achieving necessary and satisfactory federal legislation in this most critical area of human need.

Both Miss Doris S. Fraser, Director of the Bureau of Retardation and I will be pleased to answer questions of you, Mr. Chairman, and the Committee Members, if you so desire.

The subcommittee will stand in recess until 9:30 tomorrow morning.

(Whereupon, at 12:55 p.m. the subcommittee recessed, to reconvene at 9:30 a.m. Tuesday, November 11, 1969.)

MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES, 1969

TUESDAY, NOVEMBER 11, 1969

U.S. SENATE,
SUBCOMMITTEE ON HEALTH OF THE
COMMITTEE ON LABOR AND PUBLIC WELFARE,
Washington, D.C.

The subcommittee met at 9:30 a.m., pursuant to recess, in room 4232, New Senate Office Building, Senator Edward M. Kennedy presiding pro tempore.

Present: Senator Kennedy presiding pro tempore.

Committee staff members present: Robert O. Harris, staff director; James Babin, professional staff member to the subcommittee; and Jay B. Cutler, minority counsel to the subcommittee.

Senator KENNEDY. The subcommittee will come to order.

This morning, the Senate Subcommittee on Health concludes its hearings on pending legislative proposals in the area of mental retardation and other developmental disabilities.

The principal bill before the subcommittee is S. 2846, "The Developmental Disabilities Services and Facilities Construction Act of 1969," which I introduced in the Senate in August, and which is cosponsored by Senators Yarborough, Williams of New Jersey, Nelson, Mondale, Eagleton, Cranston, Hart, and Javits.

When the hearings opened yesterday, the first witnesses to testify were four representatives of the Department of Health, Education, and Welfare, who presented the views of the Administration with respect to S. 2846.

Although there is not yet an administration bill before the subcommittee, it is my understanding that such legislation is being prepared and will be introduced during the coming week.

It is my hope, therefore, that once these hearings are completed, the subcommittee will be able to act on this important legislation at the earliest opportunity.

In essence, Assistant Secretary Black and the other representatives of the administration raised three principal issues at yesterday's hearing in connection with the pending legislation. They pointed to the large amounts currently being expended by the Federal Government on other programs for the retarded and they said that the financial commitment in the pending bill should be sharply cut back. They urged us not to expand the program to include other developmental disabilities, but to continue to limit the program to those who are mentally retarded. In addition, they urged us to adopt a project grant approach for dispensing Federal funds, rather than the formula grant approach proposed in S. 2846.

A number of other witnesses at yesterday's hearing challenged the views of the administration, and emphasized the serious need to expand the scope and level of spending of our current programs.

Today, we will continue to explore these issues, with special focus on the adequacy of the existing Federal legislation. Several distinguished representatives of national organizations will speak of their deep concern for the need to stimulate greater participation by Federal, State, and local governments in this sensitive and neglected area.

In addition, Dr. Robert E. Cooke of Johns Hopkins Hospital will present a brief demonstration of the progressive approaches that have been developed under the current program of Federal support for university-affiliated facilities for the retarded.

Our first witnesses this morning will be two representatives of the National Association for Retarded Children. I am pleased to welcome you, Mr. Hayes and Dr. Boggs.

Mr. Hayes retired 2 years ago as president of CBS Radio, and he is now devoting his full time to the activities of the National Association for Retarded Children. He has had extensive experience on the Hill before the Subcommittee on Communications, and I am delighted to welcome him today in what I understand is his first appearance before the Subcommittee on Health.

Dr. Boggs is also well qualified to testify on mental retardation. She was appointed by President Eisenhower to the President's National Committee for the 1960 White House Conference on Children and Youth. In 1961, she was appointed by President Kennedy to the President's Panel on Mental Retardation. She has had extensive experience in planning for the prevention and care of the retarded, and we look forward to her testimony this morning.

Mr. Hayes, if you would like to make an opening statement we will be glad to receive it.

STATEMENT OF ARTHUR HULL HAYES, SENIOR VICE PRESIDENT, NATIONAL ASSOCIATION FOR RETARDED CHILDREN; ACCOMPANIED BY ELIZABETH M. BOGGS, PH. D., CHAIRMAN, GOVERNMENTAL AFFAIRS COMMITTEE, NATIONAL ASSOCIATION FOR RETARDED CHILDREN

Mr. HAYES. Mr. Chairman, members of the subcommittee, my name is Arthur Hull Hayes, senior vice president of the National Association for Retarded Children, and a parent. Accompanying me this morning is Dr. Elizabeth Boggs, a past president of NARC and the chairman of our Governmental Affairs Committee.

At the outset, may I express the sincere appreciation of our organization for the opportunity to appear before you today.

I would also like to express, on behalf of our membership, our heartfelt gratitude for your interest, your support and your leadership in the advancement of the cause of the retarded and the otherwise developmentally disabled.

Dr. Boggs will explain in detail our association's position on the provisions of S. 2846, and there is no one better than she to deal with both the theoretical and the substantive nature of this legislation, but I would like to take a little bit of the time allotted to us to tell you and your distinguished committee something about the National Association for Retarded Children.

NARC is less than 20 years old, Mr. Chairman. When NARC was organized, there had been little Federal activity in behalf of the retarded. Thanks to our friends in Congress, support was slowly built up during the 1950's and it has been only in this present decade that concerted Federal support for a range of necessary programs for the handicapped has become evident.

The NARC is a private, voluntary organization, composed of the parents and friends of the retarded. Our cause can best be summed up, I suppose in our slogan—which is emblazoned on our letterhead, over our office door, and—most importantly in our hearts—"The Retarded Can Be Helped."

We number about a quarter of a million members and are organized into 1,375 State and local units, distributed in every State of the Union and on several military outposts overseas.

In our more reflective moments, we like to think of ourselves as a testimonial to the power of citizen involvement and concern.

We are parents * * * we are friends * * * neighbors * * * community leaders * * * professionals * * * most of all, we are individuals, galvanized by the plight of those who cannot help themselves, motivated by the agonizing recognition of the needs of the retarded, as well as of those who love them.

There were only 40 parents who began what is now NARC. They had all been devastated by the tragedy of disability, but were all determined that somewhere, somehow, there must be an avenue of hope for their children, and, through their children, for the millions of others like them.

America was, and to some extent, still is a country which responds to little boys and pet shops, little girls, and paper dolls and pigtails.

The tragic anomaly of a handicapped child was not the subject of conversation and certainly not the subject of community concern.

Yet, Mr. Chairman, there are 6 million retarded children and adults in this country today.

Gradually, through dedication and work, our goals and accomplishments became better defined and visible. Gradually, patterns emerged, innovation was encouraged, efforts were joined in the grand march toward prevention, cure and care of the retarded and, perhaps as important, public awareness of the magnitude of the problem of retardation.

You have received documentation and will, from Dr. Boggs, receive additional information regarding both the accomplishments and the need for expansion and improvement of Public Law 88–164.

May it suffice at this point to say that this recognition of the needs of the retarded on the part of the Congress was a most significant milestone in the fight against mental retardation during these past years.

Public Law 88–164, a major piece of legislation providing facilities for the retarded, was passed unanimously in 1963 by the 88th Congress, following President Kennedy's historic message on mental retardation and mental health. This bill, as amended, expires June 30, 1970. This act was a milestone.

Now is the time, we feel, Mr. Chairman, to look at this legislation as precisely that: A milestone, that now is the time to go on further up the road to the next big milestone, the next "giant leap" into the future for the developmentally disabled.

We view S. 2846 as providing just such a forward leap and we, as volunteers, as friends, as professionals, as parents and most importantly, as an organization devoted to the disabled, thank this committee for its leadership and express our deep gratitude for your insight into the dimension of our problem.

In summary, Mr. Chairman, we view your legislation as a crucial step in the fulfillment of our goals, as set forth in our bylaws.

With your permission, I will quote:

> To promote the general welfare of the mentally retarded of all ages everywhere . . .
>
> To further the advancement of all ameliorative and preventive study, research, and therapy . . .
>
> To develop a better understanding of the problem by the public . . .
>
> To further the training and education of personnel . . .
>
> To encourage the formation of parents' groups and to coordinate their efforts and activities . . .
>
> To advise and aid parents in the solution of their problems . . .
>
> To serve as a clearinghouse for gathering and disseminating information . . .

This legislation will help immeasurably to reach these goals and will give the force of law to the principle that every disabled individual—regardless of age, color, creed or condition of disability—has a right to be understood * * * to be respected * * * and to be helped.

With your guidance and leadership, we are coming closer and closer to this goal.

Now, Mr. Chairman, may I introduce to the subcommittee—although I am sure she needs no introduction—my colleague Mrs. Fitzhugh W. Boggs.

Dr. Elizabeth Boggs is one of the founders of NARC and has been active in State and national affairs ever since. She was our first woman president in 1958–60.

Although her professional training is in the field of mathematical chemistry, she has been a full-time volunteer in health, education, and welfare for the past 15 years, and is internationally known for her grasp of the legislative aspects of mental retardation. It is an honor and a privilege for me to introduce her to this subcommittee.

Senator KENNEDY. Thank you very much, Mr. Hayes. This is a very helpful commentary. I just want to express my own personal appreciation for your comments.

I know this is a personal point of view but both President John Kennedy and Senator Robert Kennedy made your acquaintance over a period of years.

I want to express my own appreciation for your appearance here and for your great commitment to this whole program. We appreciate your statement this morning.

Mr. HAYES. Thank you very much, Senator Kennedy.

Senator KENNEDY. Dr. Boggs.

Dr. BOGGS. Mr. Chairman, we have prepared a statement for the record. With your permission, we would like to submit it. I will speak to portions of it in order to permit maximum use of the time.

Senator KENNEDY. That is fine. Your prepared statement will be printed in its entirety in the record. You may proceed to summarize it.

(The prepared statement referred to follows:)

PREPARED STATEMENT SUBMITTED BY ARTHUR HULL HAYES FOR THE NATIONAL ASSOCIATION FOR RETARDED CHILDREN

The National Association for Retarded Children wishes to record its enthusiastic endorsement of both titles of S. 2846—the Developmental Disabilities Services and Facilities Construction Act of 1969. We wish to commend the sponsors of this legislation for their initiative and their foresight in proposing legislation which addresses itself to very real problems, both human and administrative, in a manner compatible with the shape of the seventies.

As you know, our Association, despite its name, is devoted to promoting the well-being of mentally retarded persons of all ages, and all degrees of retardation, however caused. It has been estimated that there are nearly 200 distinguishable causes of mental retardation ranging from organic deficits common to all socio-economic strata—such as inborn errors of metabolism, congenital malformations of the central nervous system, birth injuries, Rh disease, and certain diseases of childhood, such as measles and whooping cough—to causes associated particularly with disadvantaging environments, such as inadequate pre-natal and peri-natal care, malnutrition, and lead poisoning. The diagnosis is important, but the needs of the retarded for services and facilities derives primarily from two characteristics common to most of those we call retarded regardless of cause: (1) impaired intellectual development with an associated reduction in ability to cope with ordinary life situations (school demands, work, self-management) and (2) long-term handicap originating early in the life and extending throughout life, in greater or less degree.

THE SPECIAL NEEDS OF THE DEVELOPMENTALLY DISABLED

Many of the retarded have other handicaps as well, for example cerebral palsy and epilepsy. The retarded with multiple handicaps need attention to all their problems, physical and mental. This has made us acutely aware of the deficiencies in the array of services needed by persons with other handicaps which share the characteristic chronicity mentioned above.

Even those with normal intelligence who have severe physical handicaps dating from earliest childhood have on-going difficulties which are distinct from those whose disabilities are acquired in adult life. The seriously cerebral palsied child, the child who is congenitally deaf or blind, the child with muscular dystrophy becomes an adult whose life has been inescapably altered by his experience of disability during the developmental years. Not only is the learning process inevitably affected, but his entry into the adult world of work and family and social life is different and much more difficult, if it is possible at all. As he ages the developmentally disabled person whether mentally retarded or physically handicapped is less likely than an adult disabled later in life to have the comfort and support of spouse and children and less likely to have an income adequate to his needs.

This Senate Committee has during the past decade brought forth legislation of enormous benefit to the handicapped. The provisions for education of the handicapped developed since 1965, the recent modifications of the Vocational Rehabilitation Act, and the greater priority to construction of rehabilitation facilities have been especially significant, but, by and large, these programs gravitate toward short-term solutions, for those pupils or clients or patients who are considered to "profit most," who can be trained or treated and then discharged as self-sufficient within a limited period of time.

These advances and this objective are important and have been vigorously supported and promoted by our Association. Nevertheless we in NARC cannot overlook the fact that there are children who are still excluded from public schools because of the severity of their retardation, young adults denied the benefits of rehabilitation at public expense because it is though it will not make them employable within two years or less, and older retardates who are placed in residential institutions of doubtful quality because the necessary supportive services in the community are not available. We are also aware that the severely disabled but mentally alert child or adult who does need a specialized living environment may be denied even that to which the retarded are entitled under State law.

For the most destitute of the adults disabled in childhood and for those deprived of previous support from an employed parent, government does provide minimal "income maintenance" under public assistance and social security, but the resources, the services which could maximize their human condition are often not there, for love or money. This is true of medical resources; it is even more true of non-medical resources. It is true for those from well-to-do families as well as for those on "welfare," and it is even more true for that large but mostly unstudied group who have very modest means but are not indigent.

It should be noted that Congress has an inclination to define programs so as to bring limited benefits to the largest number of people. Even "medicare" will not cover a continuous stay of more than 100 days in an "extended care" facility; "maximum benefit" is a polite phrase for easing children out of a State crippled children's program after the most dramatic part of their treatment is over, leaving parents to face the long haul by themselves; the seriously disabled may have "up to 18 months" of evaluation (by grace of the Secretary) under vocational rehabilitation; and, even in this Committee, federal stimulation of long-term sheltered employment opportunities for these same people has been much talked of but never acted upon. The present Mental Retardation Facilities Construction and Staffing Act follows suit, for its federal assistance for staffing any facility must decline rapidly and terminate entirely within 51 months.

RELATION OF DDSFCA TO OTHER PROGRAMS FOR THE HANDICAPPED

The victims of all these subtle and not-so-subtle discriminations are most often those with serious lifetime disabilities. It is to them, to what they need and have not received from other programs, important as they are, that we believe you are primarily directing this new imaginative piece of legislation. We see this as an intersticial bill—a bill whose benefits should flow around and between existing programs, filling both the large gaps and the smaller crevices which divide the major elements of the present system of federal aid to States and communities in meeting the needs of handicapped children and adults. The Developmental Disabilities Services and Facilities Act of 1969 should supplement and enhance—and certainly not duplicate—such programs as those now authorized under Title V of the Social Security Act (Maternal and Child Health and Crippled Children), under Title VI (Education of the Handicapped) of the Elementary and Secondary Education Act, under the Partnership for Health and Vocational Rehabilitation and Medical Facilities Construction Acts, or under programs of social services to welfare recipients. It will be necessary to conserve the resources of the new program to focus maximally on those problems of handicapped children and adults which have fallen between the boundaries of existing programs. Surely the history of this bill will show that that is your intent.

The machinery for coordination and planning that the bill provides and subsidizes should, under appropriate guidance from HEW, help to complete the jig saw puzzle of "comprehensive" planning at the level of greatest critical responsibility, in State government. The bill also assures (through its stipulations for a National Advisory Council) that voices from the State level, as well as those of "consumers" will be heard in a coherent way by the Secretary. These provisions should strengthen communication among interested parties at all levels.

THE DEVELOPMENTALLY DISABLED—WHO ARE THEY?

Our best information about those with disabilities originating in childhood which continue into adult life can be found in the data gathered over the years by the Social Security Administration relative to its so-called adult disabled child beneficiaries. Although we would not wish to limit eligibility for service under S. 2846 to those whose disability is severe enough to meet the Social Security test of disablement, we do believe that those meeting the intent of the definition of developmental disability in Section 102 of the bill (amending Section 401 of the Act) will have many comparable characteristics. In terms of the recent Social Security Survey of Disabled Adults we see S. 2846 targeted on adults who are, and children who are likely to become, either "severely disabled" or "occupationally disabled," with less attention to those who have or will have a "secondary work limitation." In mental retardation lingo, the functional definition of continued impairment and "substantial" handicap must subsume most of the moderately, severely and profoundly retarded, and a significant subgroup of the mildly retarded. On the other hand, those young people who are classified (or misclassified) as "educable" in school and who are among those who "disappear" from the ranks of the retarded by becoming socially and economically viable adults on leaving school are not primary beneficiaries of this bill although they will continue to need the best efforts of special educators and of vocational rehabilitation and manpower personnel.

By the end of this year about a quarter of a million adults will be receiving "adult child's benefits" under Social Security. Of these about two-thirds or more than 160,000, are mentally retarded, with or without another neurological impairment. Some 15 per cent are epileptic or cerebral palsied, with or without retardation. Psychoses of childhood and adolescence account for another nine per cent. Altogether these disorders account for more than 80 percent of the total. Sensory disorders, polio crippling and a variety of other diagnoses account for less than 1.5 per cent each. Although the Social Security sample is not a "random" one, since beneficiaries are only identified on the death, retirement, or disablement of the supporting parent, there is reason to believe that this composition of the group is typical of all similarly disabled persons, as is the finding that more than 85 per cent have a disability originating before their first birthday, a figure that rises to 90 percent by age six. About 28 per cent are in institutions. This figure should probably be adjusted downward to 25 or 26 percent for the adult disabled group as a whole to compensate for the higher average age of the beneficiary group.

It is of some interest to note that in one year (1965) when some 14,000 adults with mental retardation, cerebral palsy or epilepsy were awarded childhood disability allowances for the first time, there were also awarded workers' disability benefits to some 4,000 adults with the same set of disorders, indicating that this number had managed to secure enough quarters of covered employment to qualify for benefits on their own account. Of these some 1,600 were retarded.

Combining a variety of data we estimate that there may be as many as 3.5 million developmentally disabled adults and between three and four million children.

On the basis of the foregoing data it seems reasonable to assume that, of the group to which S.2846 is directed, about two-thirds are retarded and almost all the rest have neurological disorders or severe mental illnesses originating in childhood with poor prognosis for recovery.

This latter group includes the typical cases of "infantile autism." Like the retarded, these children and adults do not fit the "model" to which most mental health services in this country are addressed. Their needs are as much educational and social as medical, and even in community mental health centers they are likely to be given low priority because they do not meet the expectations of response to reatment associated with the typical emotionally disturbed child or adult. Their needs are more akin to those of neurologically impaired children and adults. And a functional definition, such as that incorporated in S. 2846, should be permitted to include them, where the State plan so specifies. In this connection it may be noted that an expert conference convened by the National Association for Mental Heatlh in February 1968 to consider the needs of this type of child, often looked upon as the stepchild of psychiatry, came up with a firm recommendation that handicapped children should be grouped, program-wise, according to their training and treatment needs rather than by diagnostic label. This basic thought is implicit in S. 2846.

PROTECTION OF INTERESTS OF THE MENTALLY RETARDED IN S. 2846

We note that Section 134 (b) (4) of the bill specifies that the State plan must:

"(A) provide for the furnishing of a range of services and facilities for persons with developmental disabilities associated with mental retardation, (B) specify the other categories of developmental disabilities which will be included in the State plan, and (C) dessribe the quality, extent and scope of such services as will be provided to persons with mental retardation and other developmental disabilities;"

We understand this to mean that the State plan *must* include provisions for the retarded and *may* include or phase in services to others with developmental disabilities other than retardation. We believe, that in light of present circumstances this proviso is only fair and realistic. The legislation which this Act will replace is limited to the retarded. Their interests should be protected in any broadening of the group to be covered. Moreover, as a practical matter, it will be impossible for the States to revise their existing State comprehensive mental retardation plans for fiscal 1971 in time to implement the new legislation in a meaningful way. This thought should also reassure the federal agencies, which are called upon by the bill to promulgate applicable regulations by March 1, 1970. We believe the Congress should expect that, for example, the State Construction plans required under the Act for 1971 should conform with what might have been required under Part C of the expiring legislation, with significant changes becoming apparent in 1972.

In connection with the anticipated phasing in of additional categories of the developmentally disabled under the State's own time table in accordance with the option offered in Section 134(b)(4), we wish to speak approvingly of the provision in Section 132(a)(2) which would require the Secretary to take some cognizance (in his formula for allotment to the States) of the inclusion or exclusion in any State's plan of persons other than the retarded. In view of the data cited above indicating that about two-thirds of the developmentally disabled are retarded, we would expect that the Secretary would augment any State's allotment by an amount up to 50 per cent additional when, and to the extent that it encompasses a range of services to eligible persons who are not retarded.

This provision means that a State does not have to penalize its retarded citizens by trying to stretch its allotment to cover more disabilities. The provision thus offers an incentive in the right direction.

On the other hand, this provision could work a serious hardship on all concerned if the President and Congress do not provide sufficient additional funds so that the allotments are not only proportionally (to others) but absolutely enlarged as the scope increases. If appropriations are not provided in 1972, and thereafter, to cover increased activity projected by the States as well as the increment which should be expected in funds for mental retardation alone, then we would expect the Secretary to exercise powers available to him under Section 139 to limit the "categories of persons for whom such services may be provided" so that expansion to new categories does not take place at the expense of those already covered.

MOVING INTO THE SEVENTIES—MAJOR ADVANCES IN S. 2846

S. 2846 reposes more trust and discretion in State administration than does PL 88–164; whereas the provisions of the present Act delineate specific solutions to one presupposed problem (the need for specialized facilities for the retarded), the Kennedy-Yarborough bill describes a problem area and invites the States to propose within broad guidelines, solutions which are most adapted to the manifest needs and to the context of existing programs within each State. Such latitude would have been premature in 1963, when the mental retardation legislation (to which S. 2846 provides a successor) was enacted; we believe, however, that it is not only timely but fitting as we approach the seventies. Thanks to intense State planning activity in mental retardation in the past five years with federal assistance, and to the growing public understanding and voluntary agency activity on behalf of the handicapped, States and communities are now ready to respond to this kind of federal incentive. The State comprehensive planning in mental retardation, when considered in conjunction with the State planning required and stimulated by other State federal programs referred to earlier, constitutes an adequate point of departure for the broadened target group contemplated in this S. 2846.

Other provisions which we applaud as improvements over the present Act include:

1. greater latitude to the States to determine their own priorities within a single grant for planning, evaluation, administration, services, and construction;
2. option to the States to utilize several State agencies in administering the funds in accordance with a comprehensive State plan;
3. A plan more responsive and less artificial reallotment provision;
4. the requirement that the State Advisory Council submit subsequent revisions of the State plan, thus preventing the by-passing of this body;
5. requirement that there be some State financial contribution to the implementation of the plan, and some limit on the extent to which local or private funds may be substituted for the State share;
6. a federal share of 80 per cent—comparable to that for Vocational Rehabilitation and for certain social services to welfare recipients—and amply justifiable considering the very considerable effort now being put forth by States in this field without federal aid, and effort which the bill specifies shall be maintained;

7. provision permitting combining funds available under this Act with other State and federal funds for complementary purposes. We see this as a means to mitigating inter-agency rivalry and increasing efficient coordination of related activities. It speaks to the concept cited earlier, of this bill as filling vacant interstices rather than creating new enclaves. It will serve those States which organize their mental retardation services in tandem with mental health without forcing this pattern on all States;

8. the requirement that States give special consideration to areas of urban and rural poverty in its priorities and through special financial and technical assistance. We also believe that these areas should receive more favorable federal matching for construction. A provision such as proposed in S. 2523 (which would be applicable to both mental health centers and facilities for the developmentally disabled) is strongly indicated;

9. the requirement that the State devise methods to assess its own effectiveness and accomplishment in meeting the needs of its developmentally disabled citizens;

10. the substitution of the concept of "services" in the most appropriate setting for the concept of "staffing a facility" and the express inclusion within this definition of a number of important services heretofore not given express sanction for federal support in this context. We hope that the Secretary will make sure that "a range of services" includes improvement and diversification of both residential and nonresidential services at all age levels.

UNIVERSITY-AFFILIATED FACILITIES

Finally we want to give warmest endorsement to Title II—with its extension and various changes in Part B of the Mental Retardation Facilities Construction Act. The concept of a university-affiliated facility for those with neurological handicaps, to be used as the focal point of an interdisciplinary professional training program was sufficiently innovative as its introduction to generate some resistance. We believe that this will turn to acceptance and enthusiasm as the "products" of these centers become more visible and useful to us all. In any case we believe it would be not only unfair but very wasteful to defer further (or refuse) funding to the dozen or more universities which in good faith began planning three and four years ago to implement an idea which was being espoused and promoted nationally. The fate of these carefully prepared but still unfunded projects hangs on S. 2846. We ourselves see these facilities as most important pace setters as well as sources of much needed expertise and personnel. We believe that every major population center should be within 100 miles of such a university-affiliated program and hope the Congress will eventually see fit to permit all areas of the country to share in the benefits of this proximity.

We are deeply grateful for the attention given this subject by the Committee, and warmly appreciative of your special contributions, Mr. Chairman, to what we are sure will be its success.

COMPARISON OF 1969 AND 1970 BUDGETS FOR THE DIVISION OF MENTAL RETARDATION

[In millions]

	Budget as it appears in appropriations documents		Budget corrected for comparability		
	1969	1970 administration	1969	1970	Increase or decrease
Staffing [1]	$8.358	$12.0	$8.358	$12.0	+$3.642
Initial	(8.358)	(4.845)	(8.358)	(7.3)	(—1.058)
Continuing		(7.105)		(4.7)	(+4.7)
Hospital improvement and inservice training	8.972	8.972	8.972	8.972	0
Rehabilitation service projects		4.5	[2] 4.1	[2] 4.5	+.4
Research	.126	.126	.126	.126	0
Construction: [1]					
Community facilities	6.0	8.031	[3] 12.0	[4] 8.031	—3.969
University-affiliated facilities	9.1		9.1		—9.1
Total	32.556	33.629	42.656	33.629	—9.027
Public Law 88-164 only	23.458	20.031	29.458	20.031	—9.427

[1] Programs authorized under title I, Public Law 88-164, pts. B, C, D.
[2] This item carried by HSMHA in 1969.
[3] This amount raised to $12.031 by floor action in H.R. 13111.
[4] Includes $6,000,000 reappropriated from 1968 cost reduction.

Dr. BOGGS. I would like to start out by paying tribute to this Senate committee. It is responsible for at least half the Federal funds—and when we think of the funds that are used for maximum leverage it is more than three-quarters of the funds—that affect the well being of the mentally retarded in the programs of the Department of Health, Education, and Welfare.

This Senate committee has during the past decade brought forth legislation of enormous benefit to the handicapped. The provisions for education of the handicapped developed since 1965, the recent modifications of the Vocational Rehabilitation Act, and the greater priority to construction of rehabilitation facilities have been especially significant.

I think I should add that, in many instances, this legislation bore the stamp of the committee much more than of the administration that proposed it. Nevertheless, a number of these programs tend to gravitate toward short-term solutions. They tend to provide assistance for those pupils or those clients or those patients who are considered to "profit most," who can be trained or treated and then discharged as self-sufficient within a limited period of time.

The exception to this statement is the legislation which is before us, the predecessor act of which addresses itself to all the mentally retarded without any such distinction.

The advances which have been made under the legislation I have cited, and the objectives that I quoted of returning people to the mainstream of society, are extremely important and have been vigorously supported and promoted by our association.

Nevertheless, we in NARC cannot overlook the fact that there are children who are still excluded from public schools because of the severity of their retardation, young adults denied the benefits of rehabilitation at public expense because it is thought it will not make them employable within 2 years or less, and older retardates who are placed in residential institutions of doubtful quality because the necessary supportive services in the community are not available.

We are also aware that the severely disabled but mentally alert child or adult who does need a specialized living environment may be denied even that to which the retarded are entitled under State law.

For the most destitute of the adults disabled in childhood and for those deprived of previous support from an employed parent, Government does provide minimal "income maintenance" under public assistance and social security, but the resources, the services which could maximize their human condition are often not there, for love or money.

This is true of medical resources; it is even more true of nonmedical resources.

It is true for those from well-to-do families as well as for those on "welfare," and it is even more true for that in large but mostly unstudied group who have very modest means but are not indigent.

It should be noted that Congress has an inclination to define programs so as to bring limited benefits to the largest number of people. Even "medicare" will not cover a continuous stay of more than 100 days in an "extended care" facility; "maximum benefit" is a polite phrase for easing children out of a State crippled children's program after the most dramatic part of their treatment is over, leaving parents to face the long haul by themselves; the seriously disabled may have "up to 18 months" of evaluation (by grace of the Secretary) under vocational rehabilitation; and, even in this committee, Federal stimulation of long-term sheltered employment opportunities for these same people has been much talked of but never acted upon.

The present Mental Retardation Facilities Construction Act follows suit, for its Federal assistance for staffing any facility must decline rapidly and terminate entirely within 51 months.

The victims of all these subtle and not-so-subtle discriminations are most often those with serious lifetime disabilities.

It is to them, to what they need and have not received from other programs, important as they are, that we believe you are primarily directing this new imaginative piece of legislation.

We see this as an interstitial bill—a bill whose benefits should flow around and between existing programs, filling both the large gaps and the smaller crevices which divide the major elements of the present system of Federal aid to States and communities in meeting the needs of handicapped children and adults.

The Developmental Disabilities Services and Facilities Construction Act of 1969 should supplement and enhance—and certainly not duplicate—such programs as those now authorized under title V of the Social Security Act (Maternal and Child Health and Crippled Children), under title VI (Education of the Handicapped) of the Elementary and Secondary Education Act, under the Partnership for Health and Vocational Rehabilitation and Medical Facilities Construction Acts, or under programs of social services to welfare recipients.

It will be necessary to conserve the resources of the new program to focus maximally on those needs of handicapped children and adults which have fallen between the boundaries of existing programs.

It should be pointed out here that when we speak of these needs we have reference not merely to the fact that some people don't qualify for some of these programs, but that many people qualify only part of the time or for a partial program.

Thus there are gaps in the services to an individual even though he may be eligible some of the time for some of the help.

We hope, we surely must expect, that the history of this bill will show that it is your intent that its benefits focus on the gaps and lacks and that it should not be used as a source of interagency rivalry on the part of people who have been suggesting that this would duplicate other legislation.

The machinery for coordination and planning that the bill provides and subsidizes should, under appropriate guidance from HEW, help to complete the jigsaw puzzle of "comprehensive" planning at the level of greatest critical responsibility, in State government.

The bill also assures—through its stipulations for a National Advisory Council—that voices from the State and local level, as well as those of "consumers" will be heard in a coherent way by the Secretary.

These provisions should strengthen communication among interested parties at all levels.

There has been quite a bit of discussion in these hearings already as to what is meant by "the developmentally disabled."

Candor forces me to say some of the remarks made yesterday reflect failure to read the language of the bill. Certainly it focuses on those who have a substantial continuing handicap.

Many minor physical disabilities or physical handicaps which originate congenitally, for example, do not constitute a significant continuing disability into adult life. Many are remediable by appropriate efforts in childhood.

We are in favor of utmost remediation, and in many instances this can be provided under crippled children's services or under vocational rehabilitation services now available.

We wish to point out, nevertheless, that there still exists a group of people who, because of the chronicity of their disability, continue to be shoved aside because they do not seem to show such a dramatic response to treatment.

Our best information about those with disabilities originating in childhood which continue into adult life can be found in the data gathered over the years by the Social Security Administration relative to its so-called adult disabled child beneficiaries.

Although we would not wish to limit eligibility for service under S. 2846 to those whose disability is severe enough to meet the social security test of disablement, we do believe that those meeting the intent of the definition of developmental disability in section 102 of the bill—amending section 401 of the act—will have many comparable characteristics.

In terms of the recent social security survey of disabled adults—which was not confined to those eligible for disability benefits—we see S. 2846 targeted on adults who are, and children who are likely to become, either "severely disabled" or "occupationally disabled," with less attention to those who have or will have a "secondary work limitation."

In mental retardation lingo, the functional definition of continued impairment and "substantial" handicap must subsume most, if not all, of the moderately, severely and profoundly retarded, and a significant subgroup of the mildly retarded.

On the other hand, those young people who are classified—or misclassified—as "educable" in school and who are among those who "disappear" from the ranks of the retarded by becoming socially and economically viable adults on leaving school are not primary beneficiaries of this bill although they will continue to need the best efforts of special educators and of vocational rehabilitation and manpower personnel.

By the end of this year about a quarter of a million adults will be receiving "adult child's benefits" under social security. Of these about two-thirds or more than 160,000, are mentally retarded, with or without another neurological impairment. Some 15 percent are epileptic or cerebral palsied, with or without mental retardation. Psychoses of childhood and adolescence account for another 9 percent. Altogether these disorders account for more than 80 percent of the total.

Sensory disorders, polio crippling, and a variety of other diagnoses account for less than 1.5 percent each. Although the social security sample is not a "random" one, since beneficiaries are only identified on the death, retirement, or disablement of the supporting parent, there is reason to believe that the diagnostic composition of the group is typical of all adults similarly disabled in childhood. The same is true of the finding that more than 85 percent have a disability originating before their first birthday, a figure that rises to 90 percent by age 6.

About 28 percent are in institutions. This figure should probably be adjusted downward to 25 or 26 percent for the adult disabled group as a whole to compensate for the higher average age of the beneficiary group, because the beneficiaries are on the average somewhat older than the total adult disabled group.

Combining a variety of data we estimate that there may be as many as 3.5 million developmentally disabled adults and between 3 million and 4 million children.

On the basis of the foregoing data it seems reasonable to assume that, of the group to which S. 2846 is directed, about two-thirds are retarded and almost all the rest have neurological disorders or severe mental illnesses originating in childhood with poor prognosis for recovery. This latter group includes the typical cases of "infantile autism."

This subject of definition has been brought up because of the fear that the broadening of the coverage of the act as compared to the present act would dilute the attention and focus for the mentally retarded.

We would concur that there is a danger in this respect and we would like to comment on that point.

You will note that section 134(b)(4) of the bill specifies that the State plan must "(A) provide for the furnishing of a range of services and facilities for persons with developmental disabilities associated with mental retardation, (B) specify the other categories of developmental disabilities which will be included in the State plan, and (C) describe the quality, extent and scope of such services as will be provided to persons with mental retardation and other developmental disabilities;".

We understand this to mean that the State plan must include provisions for the retarded and may include or phase in services to others with developmental disabilities other than retardation.

We believe, that in light of present circumstances this proviso is only fair and realistic. The legislation which this act will replace is limited to the retarded. Their interests should be protected in any broadening of the group to be covered.

Moreover, as a practical matter, it will be impossible for the States to revise their existing State comprehensive mental retardation plans for fiscal 1971 in time to cover additional disabilities under the new legislation in a meaningful way.

This thought should also reassure the Federal agencies which are called upon by the bill to promulgate applicable regulations by March 1, 1970.

We believe the Congress should expect that, for example, the State construction plans required under the act for 1971 should conform with what might have been required under part C of the expiring legislation, with significant changes first becoming apparent in 1972.

In connection with the anticipated phasing in of additional categories of the developmentally disabled under the State's own timetable in accordance with the option offered in section 134(*b*)(4), we wish to speak approvingly of the provision in section 132(*a*)(2) which would require the Secretary to take some cognizance (in his formula for allotment to the States) of the inclusion or exclusion in any State's plan of persons other than the retarded.

In view of the data cited above indicating that about two-thirds of the developmentally disabled are retarded, we would expect that the Secretary would augment any State's allotment by an amount up to and not to exceed 50 percent additional when, and to the extent that it encompasses a range of services to eligible persons who are not retarded.

This provision means that a State does not have to penalize its retarded citizens by trying to stretch its allotment to cover more disabilities. The provision thus offers an incentive in the right direction.

On the other hand, this provision could work a serious hardship on all concerned if the President and Congress do not provide sufficient additional funds so that the allotments are not only proportionally (to others) but absolutely enlarged as the scope increases.

If appropriations are not provided in 1972, and thereafter, to cover increased activity projected by the States, as well as the increment which should be expected in funds for mental retardation alone, then we would expect the Secretary to exercise powers available to him under section 139 to limit the "categories of persons for whom such services may be provided" so that expansion to new categories does not take place at the expense of those already covered.

Now the Administration yesterday was taking the position that they could not possibly provide these additional funds that would be necessary and, therefore, the legislation should not proceed in this direction.

Mr. Chairman, we think this is a very shortsighted view. The purpose of substantive legislation which comes before this committee, as distinct from appropriations legislation, is to set the pattern of growth in a logical way for the future.

We do believe that it is important to develop legislation stage by stage in a logical way and to lay the basis for future programing.

The fact that we have what we all hope will be a temporary stringency with respect to funds should not be used as an excuse for scrapping the foundations of a good program and failing to build toward the time when we will have more ample funds to carry out a logical and appropriate program.

We believe that we need a transitional phase in this legislation which will move us toward the concept of a functional definition of the group which is in need of similar—not identical but similar—services, services which will be similarly organized, and that we would in any event (even with ample funding) need to have a period of phasing of the newly covered groups. This has to be done in an orderly fashion and in a fashion which gives the States some latitude in adjusting their complex groupings of services which have some impact on the disabled.

To go backward, to disregard the progress that has been made in the last 5 years, and to act as though the effort which the States have, in response to the Federal request for planning, put into organizing State agencies so as to address themselves to needs—to act as though this had never happened and to go back to the project grant approach which was appropriate in 1962 and 1963, would in the opinion of many of us be a very sad backward step.

We want to point out that S. 2846 reposes more trust and discretion in State administration than does Public Law 88–164 which it will replace.

Whereas the provisions of the present act delineate specific solutions to one presupposed problem (the need for specialized facilities for the retarded), the Kennedy-Yarborough bill describes a problem area and invites the States to propose within broad guidelines, solutions which are most adapted to the manifest needs and to the context of existing programs within each State.

Such latitude would have been premature in 1963, when the mental retardation legislation (to which S. 2846 provides a successor) was enacted; we believe, however, that it is not only timely but fitting as we approach the 70's, to make this transfer of responsibility.

The program is getting larger and more complex and the idea that the Federal Government is the repository of all knowledge in these matters and that it can carry on a dialogue with local agencies and tie its strings around every $20,000 grant is just out of date.

It is important in this area that local initiative be encouraged and that the money reach the people in the local communities. I think the language in this bill makes it clear that it is intended to do that, and that the States can be expected to respond, as they have heretofore under 88–164, in that regard.

Thanks to intense State planning activity in mental retardation in the past 5 years with Federal assistance, and to the growing public understanding and voluntary agency activity on behalf of the handicapped, States and communities are now ready to respond to the kind of Federal initiative and incentive proposed in S. 2846.

The State comprehensive planning in mental retardation, when considered in conjunction with the State planning required and stimulated by other State-Federal programs referred to earlier, constitutes an adequate point of departure for the broadened target group contemplated in this bill, S. 2846.

We have listed in our prepared testimony a number of other provisions in the bill before us which we regard as real improvement over the present act.

I will refrain from touching on all of them but I wish to call attention to a couple. In the first place, there is a requirement that there be some State financial contributions in the implementation of the plan and some limit on the extent to which purely local or private funds may be substituted for the States' share.

Under the present act there is really no requirement that the State government put up any money excepting for administration.

We believe that the requirement for State contribution will strengthen the program and strengthen the State-local partnership.

We want to point out that there is a requirement that the States give special consideration to areas of urban and rural poverty and that it give special financial and technical assistance to those areas.

We also agree with the administration that these areas should receive more favorable Federal matching for construction. The figure cited has been up to [illegible]0 percent.

This is in fact considered by us to be part of S. 2846 for the reason that the provisions of S. 2846, if enacted, will be governed by the specifications as to the Federal share which are contained in title IV of the existing act as it may be amended.

It is proposed by the community mental health centers bill which is pending, S. 2523, to change that Federal share in the direction that we have just indicated and the administration supported that change when it testified on the mental health bill. If, for any reason, this increased Federal share for poverty areas is provided for mental health by a mechanism other than amendment of section 402 of Public Law 88-164, then a corresponding provision should be included in S. 2846.

Therefore, if this committee in its markup—which we anticipate shortly—of the mental health bill follows its own advice and that of the administration it will automatically provide for a revised and more favorable Federal share for areas of urban and rural poverty in respect to mental retardation construction.

Of course, if part C is allowed to lapse without extension or substitution, that won't be the case. Your bill provides a new part C; a substitution.

Finally, I want to mention and reinforce that the bill provides for the substitution of a concept of "services in the most appropriate setting" for the much more limited concept, that of "staffing of the facility".

The express inclusion within this definition of a number of important services heretofore not given express sanction for Federal support in this context is to us very important.

I refer here, for example, to protection services, to information and referral services, to specialized aspects of generic services which are often carried on elsewhere than in facilities for the mentally retarded.

We also hope that the Secretary will make sure that in interpreting the meaning of the term "a range of services" he will include diversification of both residential and nonresidential services at all age levels.

Mr. Chairman, title II on university-affiliated facilities is to us of extreme importance. You heard very eloquent testimony on this subject yesterday. We support the extension and expansion of that provision, part B of the present act, and support the testimony wihch was given by the people closest to that problem, the directors of the university-affiliated facilities.

I'd like to stress two aspects, however. First, we find shocking the refusal of both the Johnson and Nixon administrations to request any funds in fiscal 1970 for construction of university-affiliated facilities even though there are approved and approvable applicants. This is compounded by the failure of this administration to give any assurances that these applicants will be given the slightest consideration under its proposals outlined yesterday. (Indeed if it does fund any such facilities out of its proposed current level of funding of Public Law 88-164, it would cause further serious curtailment of the community programs.)

We find this behavior shocking and disturbing because it means that the leaders in HEW are prepared to consider expendable the time and energy already invested by literally hundreds of key professionals in the short-staffed field of mental retardation and related impairments. These are the men and women who have been, in good faith, developing exciting new plans in response to the Federal leadership that seemed to be so clear after Congress gave unanimous support to the UAF idea in 1963 and 1967.

A "now you see it, now you don't" approach to this issue will have a very disquieting effect on the already strained relations between the Federal Government and the universities.

Many millions of private and State dollars have been invested in planning programs and facilities and in assembling the initial interdisciplinary staff in anticipation that the Federal Government meant business. It may be argued that the Federal Government is giving lipservice to controlling expenditures while it contributes to inflation by causing dollars spent at other levels to be wasted.

The same observation applies also to the structures and plans brought into being at the State and local levels, in response to the inducement offered under part C.

Thank you.

Senator **Kennedy**. That is very comprehensive testimony, Dr. Boggs. I want to express our great appreciation for your comments this morning, and for your help in the past in developing many of the ideas in this field.

You have shown once again this morning why both President Eisenhower and President Kennedy exercised such fine judgment in expressing their confidence in your guidance on the problems of the retarded and on our youth.

Let me express our appreciation to you.

I believe you heard the administration's comments yesterday on S. 2846 and the formula grant approach. Can you give us your own feeling about your reaction to this?

Dr. **Boggs**. Frankly, Mr. Chairman, listening to the administration testimony yesterday was one of the most discouraging experiences I have had in 10 to 12 years in dealing with Federal legislation.

It was really—well, let me symbolize it this way: This morning I went to pick up a copy of MR68 which is last year's report of the President's Committee on Mental Retardation.

I found the pages were stuck together. Somebody had spilled a glass of water on it. It was symbolic to me. Cold water has been thrown upon the hopes that we have entertained for the Federal commitment to the mentally retarded and the pages were stuck together. The report was closed. It could not be further read, further heeded.

Yesterday's was a very discouraging experience. It was discouraging because I could not help but feel that this administration was making policy hastily at a level in the administration, at a locus in the administration, where there is obviously little understanding of the true problem.

It seemed to me that this was a careless brushing off of a need which has taken a long time to make itself manifest and visible. It was a careless way of abandoning any attempt to build on the impressive State level commitment and technical competence which has been nurtured, in the past 5 years especially, by the Federal Government.

It was inconsistent in its approaches to the Federal-State relationship. It was a way of saying to the State agencies and the Governors and the legislatures, "The Federal Government is a fickle acquaintance; it is not a solid partner; don't count on anything we say or tell you because 2 years later we may change our mind."

The administration witnesses said they would guarantee under this project grant approach that each State would get at least as much as it would get in 1970 under the construction provision which, according to the administration's request, is the magnificent total of $8 million for construction for the entire Nation (an amount that is about what it takes to build one good-size office building), and that this amount is going to be distributed among all the States. It means that 27 States can count on getting $100,000 and those who get a little more are proportionately very underfunded.

It means that California can only be guaranteed one-fifth as much per capita as the neighboring State of Nevada.

It means that a poor State such as Mr. Black was pleading for yesterday, for example the State of Mississippi, can be sure of $9,000 more than Nevada, which I also cited, or for that matter, $9,000 more than Alaska.

Of course, to be fair to the administration, what they mean to do is to take additional money and parcel it out as they see fit, without any assurances, but if you are doing State planning you need some guarantee and what I just described is all the guarantee they would get under the administration proposal.

It says to me that an administration which has been in office for 11 months and has had excellent review machinery supplied to it, already in being in the Federal structure, provided by previous administrations; which inherited a President's Committee composed of the outstanding people in the Nation, that this administration is now saying, "Oh, gentlemen, we should look at this program; give us time to study it some more."

This is a very discouraging experience for those of us who have been in the field.

Senator **Kennedy**. I suppose it is particularly discouraging, since we know that the present program is going to expire next year. It is not simply a question of whether we start on such a program de novo today.

There must be some kind of machinery that tells the Federal agencies that certain legislation is going to expire.

Dr. **Boggs**. This is true of all the health legislation and particularly true of this. I don't think it is any secret that the outgoing administration had the good grace to draft legislation in this area and leave it on the desk.

This is not a partisan area. The only real crunch issue was, how much could we authorize, how much money could we spare?

This, as experience has well shown, is an issue that confronted President Johnson and President Nixon alike.

This effort, this ongoing effort of the Federal machinery has been available since January, but no attention was paid to it.

It is for this reason that we so welcome the initiative of this committee which, as I said earlier, has on several previous occasions come to the rescue when the administration has failed in its responsibility.

I am not speaking in a partisan sense here. It has happened several times.

Senator **Kennedy**. One of the responses in Mr. Black's testimony is that some $585 million is already being spent on the retarded. This figure certainly startled me. We received some background information in a lengthy report which was made a part of the record yesterday.

What is your reaction to this statement? They say we are already spending $585 million. Therefore, they said, the dollar figure in S. 2846 is unrealistic, especially with our current fiscal problems.

What is your reaction to these statements?

Dr. Boggs. This is like saying medicare provides services to people. It does provide services to people but only those over 65.

The money being spent by the Federal Government on mental retardation is of great value; it is like medicare, it is important, it addresses itself to the problem, but it does not address itself to all the problems in the field of mental retardation.

There are gaps in this system. But let me speak to that $585 million figure. That, as I understand, came as a shock to you and members of the committee. However, this is a figure we have been familiar with for some months because we are very much interested and concerned that all the agencies of government address themselves to the mentally retarded in a fair and equitable way. More often than not, the retarded have been screened out of programs to which they are entitled as citizens.

We have spent the past 10 years making sure that educators educate the handicapped and that health people look at the long-term disorders as well as the acute conditions, and so on.

We believe that the mentally retarded should get their share within the whole range of existing programs and that the special agency—the Division of Mental Retardation—should deal primarily with those problems which were either interagency in nature or did not fall naturally in the responsibilities of the other agencies.

Now, for that $585 million of expenditures for 1970. Mr. Black said we ought to look at his $20 million for Public Law 88–164 in the context of this $585 million. I ask you to look at this $585 million in the context of the total HEW program.

This $585 million includes not only the regular appropriations for the Department but also the trust funds that are expended for the retarded who are entitled to social security. That means that $585 million is part of $69 billion. That is what it is—less than 1 percent—and yet Mr. Black will cheerfully tell you that 3 percent of the citizens of this country are mentally retarded.

So I am not so impressed by $585 million as being that much of a commitment. Furthermore, I think we need to analyze this figure a little bit.

Incidentally, Mr. Chairman, the figures that Mr. Black quoted are obviously the same as were given in the testimony of the Secretary before the House Appropriations Committee earlier this year and I have taken the liberty of duplicating the table on three pages out of that testimony which summarizes these programs.

Senator Kennedy. We will make that table a part of the record.

Dr. Boggs. Good.

(The table referred to follows:)

Obligations for Mental Retardation Programs by Agency Designation, Department of Health, Education, and Welfare

Fiscal Years 1966-1970
(Thousands of Dollars)

AGENCY	1966	1967	1968	1969 Estimated	1970 Estimated
Health Services and Mental Health Administration					
Comprehensive Health Planning and Services . . .	$ -0-	$ 5,485	$ 4,071	$ 3,475	$ -0-
Mental Health Research and Services	11,636	8,279	1,556	1,627	1,495
National Health Statistics	19	21	21	6	-0-
Total, Health Services and Mental Health Administration	11,655	13,785	5,648	5,108	1,495
National Institutes of Health					
Neurology and Stroke Activities	22,028	19,473	21,384	21,950	21,600
Child Health and Human Development	8,500	12,134	13,680	15,608	16,486
Grants for Construction of Health Research Facilities	6,234	6,026	-0-	-0-	-0-
Total, National Institutes of Health	36,762	37,633	35,064	37,558	38,086
Office of Education					
Elementary and Secondary Education Activities. .	20,963	27,512	30,589	37,218	40,438
Educational Improvement for the Handicapped . .	8,977	10,024	17,410	27,200	29,600
Education Professions Development	-0-	-0-	-0-	129	150
Libraries and Community Services	-0-	-0-	-0-	90	90
Research and Training	255	165	38	25	20
Vocational Education	-0-	-0-	-0-	-0-	11,500
Total, Office of Education	30,195	37,701	48,037	64,662	81,798

AGENCY	1966	1967	1968	1969 Estimated	1970 Estimated
Social and Rehabilitation Service					
Vocational Rehabilitation					
Grants to States	$13,764	$22,855	$27,800	$40,860	$61,760
Research and Demonstration Activities	3,713	3,764	2,867	2,909	3,035
Innovation and Expansion Grants	311	475	570	574	574
Facility Improvement Grants	283	1,302	3,400	3,700	3,900
Training and Traineeships	1,501	1,700	1,760	1,760	1,760
Rehabilitation Facilities and Construction Grants	325	1,000	866	828	472
Mental Retardation					
Staffing Grants	-0-	-0-	-0-	8,358	12,000
Hospital Improvement	8,909	8,790	8,610	8,972	8,972
Rehabilitation Service Projects	-0-	-0-	-0-	-0-	4,500
Research	36	32	126	126	126
Construction	20,562	32,339	16,680	27,113	13,531
Planning	2,120	1,523	1,394	-0-	-0-
Maternal and Child Health and Welfare					
Grants to States	11,220	11,843	12,740	12,990	12,990
Training and Traineeships	5,865	9,865	12,865	14,865	17,065
Research and Demonstration	2,759	2,957	3,300	3,300	3,200
Medical Assistance - Grants to States 1/	13,100	28,500	30,000	75,000	100,000
Public Assistance - Grants to States 2/	37,900	51,000	55,000	65,000	75,000
Total, Social and Rehabilitation Service	122,368	177,945	177,978	266,355	318,885
Social Security Administration					
Estimated Benefit Payments from Trust Funds	84,500	93,600	107,900	131,300	141,700
Trust Fund Obligations Incurred to Adjudicate Claims of Beneficiaries	1,800	1,600	1,900	2,400	2,600
Total, Social Security Administration	86,300	95,200	109,800	133,700	144,300

AGENCY	1966	1967	1968	1969 Estimated	1970 Estimated
Office of the Secretary					
Secretary's Committee on Mental Retardation [3]	$(238)	$ (105)	$ (128)	$ (160)	$ (160)
President's Committee on Mental Retardation [4]	-0-	(316)	577	580	605
Total, Office of Secretary	--	--	577	580	605
Total, Services and Grants	163,080	216,064	212,304	309,263	365,869
Total, Income Maintenance	124,200	146,200	164,800	198,700	219,300
GRAND TOTAL, ALL FUNDS	287,280	362,264	377,104	507,963	585,169

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[1] These expenditures are based on present experience with six States claiming an average of approximately $5 million per State for a full year for the care of the retarded in State institutions. Fifteen States for 1969 and twenty States for 1970 are estimated in the amounts shown. There is presently no method available for estimating title XIX payments for the care of the retarded outside of State institutions.

[2] Exact information is not available on the costs due to mentally retarded people who are receiving public assistance because data secured does not single out this one cause as a factor of disability or dependency. However, it is known that mental retardation is an important cause of disability for those receiving aid to the permanently and totally disabled under the Federal-State public assistance program. The amounts shown here are estimates based on a constant percentage of total payments under this part of the program.

[3] Shown as non-add items since they were derived from funds available to other agencies for mental retardation activities.

[4] Beginning in 1968 this item is included in direct funding as a line item.

Dr. Boggs. Also, there is another breakdown of the same sum. I am going to address myself to that, too. In this excellent annual publication called "Mental Retardation Activities of the Department of Health, Education, and Welfare, January 1969," there is a breakdown of this same $585 million according to activity.

(The material referred to follows:)

OBLIGATIONS FOR MENTAL RETARDATION PROGRAMS BY ACTIVITY DESIGNATION, U.S. DEPARTMENT OF HEALTH EDUCATION, AND WELFARE, FISCAL YEARS 1968–70

[In thousands of dollars]

Activity	Fiscal years—		
	1968 actual	1969 estimated	1970 estimated
Services:			
Health Services and Mental Health Administration	2,661	1,738	0
Office of Education	38,089	53,218	69,438
Social and Rehabilitation Service	81,359	148,272	200,014
Total	122,109	203,228	269,452
Training of personnel:			
Health Services and Mental Health Administration	2,291	2,688	870
National Institutes of Health	12,476	13,066	12,449
Office of Education	9,000	10,129	10,150
Social and Rehabilitation Service	16,386	18,807	23,507
Total	40,153	44,690	46,976
Research:			
Health Services and Mental Health Administration	644	630	625
National Institutes of Health	22,588	24,492	25,637
Office of Education	948	1,225	2,120
Social and Rehabilitation Service	6,293	6,335	6,361
Total	30,473	32,682	34,743
Construction:			
Social and Rehabilitation Service	17,546	27,941	14,003
Total	17,546	27,941	14,003
Planning:			
Social and Rehabilitation Service	1,394	0	0
Total	1,394	0	0
Income maintenance:			
Social and Rehabilitation Service	55,000	65,000	75,000
Social Security Administration	109,800	133,700	144,300
Total	164,800	198,700	219,300
Other:			
Health Services and Mental Health Administration	52	52	0
Office of Education	0	90	90
Total	52	142	90
Secretary's Committee on Mental Retardation [1]	(128)	(160)	(160)
President's Committee on Mental Retardation	577	580	605
Total	577	580	605
Grants and services	212,304	309,263	365,869
Income maintenance	164,800	198,700	219,300
Grand total, all funds	377,104	507,963	585,169

[1] These amounts are shown as non-add items since they are derived from funds available to several agencies of the Department of Mental Retardation activities.

Dr. Boggs. The first sheet represents the way it was presented to the Appropriations Committee. The second is broken down differently. Both of these are important in the way they reveal the thrust of funding.

Now Mr. Black looked at the bottom of that long sheet (first table) and he said $365,865,000 of this goes to what he called services and grants. That excluded the so-called income maintenance provision.

He said this was $56 million more than last year. Let me just show you where that $56 million comes from. In the first place, $25 million of it comes from a phony line item called medical assistance. I will explain that if you ask me. It is the line item called "Medical Assistance grants to the States, $100 million."

That is an estimate if ever there was one. I just want to tell you that 90 percent of that money is a well disguised revenue-sharing grant to the States. It is replacing State money that has been spent for the retarded heretofore. Very little of it is upgrading services for the retarded. Therefore let us take the $25 million increase for that out of the $56 million overall increase claimed by Mr. Black. That leaves $31 million.

Now, Mr. Black didn't tell you, in presenting this material, that this material was developed and presented to the House Appropriations Committee before the Nixon budget cuts came along. So let us take off $11 million total for Nixon budget cuts. This is composed of $6 million out of the retardeds' share of vocational rehabilitation and $2.2 million out of the training programs of the university-affiliated facilities that you heard about yesterday, $1 million out of the $3 million earmarked for research in the NICHD and another $1 million of unearmarked money for research in two of the institutes and a half million of vocational rehabilitation training money. All these were cut from the $585 million by the President.

I am taking these as the proportion attributable to the retarded, not the total cuts of these programs. Then there is another half million dollars or so of miscellaneous cuts in libraries and community services, and so forth. That makes at least $11 million that the Nixon administration took out. That takes this $585 million down to $574 million and it takes the $56 million "increase" down to $20 million.

Now, there is a $15 million increase over last year in vocational rehabilitation which is mandated under the legislation this committee prepared. There is $11.5 million new amount for vocational education of the handicapped which is also mandated by this committee. This is a total of $26½ million that is in this 1970 budget that was not in the 1969 budget, as a result of the mandate in vocational education and vocational rehabilitation that this committee enacted. If you subtract that from Mr. Black's phantom increase you get a minus number. You are down to minus $6.5 million, an overall reduction in what is available for service, and training in mental retardation, other than in vocational program.

Another way to look at this is through the two page table you have there (second table); you will notice that $585 million covers research, training, construction, services and so forth.

Research, we in NARC have supported research diligently. Training is tremendously important and our testimony in support of title II should indicate that. But when you talk about what is happening to the retarded who are here and now, you have to get down to the service area.

In the second table, at the top you will notice that $269 million is listed for services. If you take out the $100 million phony money I spoke of, that gets you down to $169 million.

Most of that is education and vocational rehabilitation. Both vocational and rehabilitation funds are funds we have fought for. We want them, we need them, but they don't do everything for the mentally retarded of all ages. They don't reach very many preschool children and they don't reach the retarded over 30.

So there are lots of unmet needs when you take that service figure. That is what title I of this bill is addressed to—provision of service.

Senator KENNEDY. What about the relation of the State plan required in S. 2846 to all the other so-called "comprehensive" plans this committee hears about? Should we make this State plan consistent with the State partnership for health plan, for instance?

Dr. BOGGS. We certainly hope that the State plans for those with developmental disabilities will be seen as being coordinated with, rather than subordinated to, any other major State plans in health, or mental health, or education, or rehabilitation, or welfare, because the developmental disability plan is related to all of them but cannot be subsumed entirely under any one of them.

Those two tables we just discussed, particularly the first one, indicate that the mentally retarded are identified and served in vocational rehabilitation, in maternal and child health and crippled children's services, in special education, in public assistance, and also in a few adult health programs. I expect that Dr. Ganzer, when he testifies later, will be able to show you that quite a few retarded children and adults get psychiatric services in mental hospitals—40 or 50,000, maybe. The position of NARC has always been that the mentally retarded should as far as possible get their health services from health agencies, their social services from our social agencies, their education from public and private schools, and so on. But some of their needs are too specialized and for one reason or another fall outside the competence or mission of the generic agencies. And all the pieces have to be brought together in a planned way from the point of view of the retarded, individually and collectively. No one agency can do it all.

We would recommend that the committee make clear that the State plan for the developmentally disabled should specify what is being done or will be done for the target group under other major State-Federal plans and how the DDSFCA plan will complement, rather than duplicate any of those plans. However, we would not favor a Federal requirement for multiple agency clearance of individual projects within the State plan.

Of course, there already is a general requirement for clearing construction projects with metropolitan and other physical planning bodies, which would have to be respected.

Senator KENNEDY. How about leveling off this program at $20 or $25 million as Mr. Black suggested yesterday, in view of the amounts that are being spent in the other programs?

Dr. BOGGS. "Leveling off" is a very arbitrary idea. It takes no account of the history of a program, of its maturity. It's like saying to a family "As of now, and henceforth, each member will be allowed no more to eat than he had to eat last year" without regard to whether the person is 6 months or 6 years or 60 years old. Our program is a toddler who should be growing. The nearest comparable program, the community mental health centers program, has had a head start (due to various historical accidents); its staffing funds first became available in fiscal 1966 and have grown every year since; the first mental retardation staffing grants were awarded only at the very end of 1969. So leveling off for both programs is premature, but in mental retardation it is a disaster. Actually, it isn't even leveling off; it's reduction that is proposed.

As I've indicated already. This program is not interchangeable with others affecting other aspects of the problem. It zeros in on unique needs not otherwise addressed by the Federal Government.

Senator KENNEDY. In its reports "MR68" and "MR69" the President's Committee made a number of recommendations in terms of improving services and facilities. Is the administration's position consistent with the recommendations in these reports?

Dr. BOGGS. MR68, reaffirmed by MR69, focused on three main priority areas. One of these is the mentally retarded in poverty areas. Mr. Black made some references to that. I think his interpretation of the situation showed a lack of understanding of the problem but he did quote that finding of the President's Committee.

The second priority area was residential care. I don't think the administration's proposals address themselves in any substantial way to the problems in that area. I believe that S. 2846 can and should; it certainly is intended to cover both residential and nonresidential services and provide assistance in diversifying the range of living arrangements; the bill adds (to the definition of services) "specialized living arrangements" that focus on the need for so-called "alternatives" to the standard type of institutional care.

You bill, Mr. Chairman, addresses itself to these problems. The administration approach is a very spotty one at best. They didn't say a word yesterday that indicated to me that they appreciate the nature of this problem of residential care.

Finally, MR68 spoke to the manpower question. Probably the most important single tool that we have at present in the manpower picture is the university-affiliated facility idea. You heard yesterday what the universities are doing and the real changes that are being brought about, both in the training programs themselves and in the byproduct effects on the service areas, but this was brushed aside by the administration.

MR69 talks about building on the past, building and moving into the 70's. Let me quote their exact language.

It is

> "Time to consider carefully and begin building the urgently needed programs for the retarded that must come into being during the 1970's. Time to renew our national resolve to bring the mentally retarded into full participation in daily life and work as their individual capabilities permit.
>
> Time to press on in quests for ways of preventing mental retardation.

I don't think that the administration witnesses really address themselves to that either.

It is true that the Deputy Assistant Secretary for Health did mention prevention and I was glad to hear he was aware of this need. But prevention depends on research and on training of manpower.

Primary prevention is not a primary objective of title I of this bill. Secondary prevention is, because early services are important to secondary prevention.

Senator KENNEDY. What is your feeling about the administration's position that by project grants rather than formula grants, they will be able to focus the limited resources in the areas of greatest need—for example, in poverty areas?

Dr. Boggs. Let me say, first of all, that every major Federal program which involves activities which have to be carried on at the State and local level should, in our opinion, consist of both formula grant money and project grant money.

The reason there is no project grant provision in title I, I am sure, is that there already exists a broad—by that I mean broad in terms of its applicability—project grant authority available to the Division of Mental Retardation.

Senator Kennedy. Is that under the Mental Retardation Act?

Dr. Boggs. No, it derives from a special phrase added in 1968 to section 4 of the Vocational Rehabilitation Act. It was incorporated as an amendment proposed by Senator Hill. It makes possible project grants related to rehabilitation of the retarded without limitation to vocational rehabilitation.

Senator Kennedy. How much money is involved?

Dr. Boggs. For fiscal 1970, $4.5 million has been requested. This year is the 1st year under which project grants will be funded under the "section 4" authority. This is called "rehabilitation service projects" in the table we have appended to our prepared statement. It does everything that the administration talks about except provide project grants for construction.

It provides all the other things, training projects, service projects, demonstration projects, and so forth. It is a very useful little thing.

What do they ask for? For $4½ million for projects for the entire country for 1970. That could be expanded without any more attention to substantive legislation.

Senator Kennedy. They have not had a project grant authority before?

Dr. Boggs. The Division had a project grant authority when it was part of the Bureau of State Services of the Public Health Service. It began in 1963–64 and was gradually built up to $5.5 million in fiscal 1967. Then after the Partnership for Health Act, funds were no longer available specifically for mental retardation, and the Division was without general project authority and leverage in fiscal 1968 and 1969.

Senator Kennedy. Do you believe that there should be a clearly spelled-out project grant authority in S. 2846?

Dr. Boggs. While not absolutely necessary, such an authority would strengthen the bill if it were not allowed to diminish the basic formula grant provisions.

Senator Kennedy. Do you believe that project grants are needed to reach the areas of greatest need?

Dr. Boggs. Not necessarily, not federally administered project grants; with a properly structured formula grant, you can assist the States in doing the job in the areas they identify as high priority areas. Don't think the States don't know where these problems are.

In further response to your question, the important things are, I think, first, the fact that project grant authority alone is not enough; if the project grant authority were big enough to do the job in deprived areas, it should not be a project grant authority. Secondly, Secretary Black yesterday showed a lack of understanding of the nature of the problem in the so-called poverty area when he kept talking about the necessity for putting facilities "in the places where 75 percent of the retarded are."

Now, in MR68 there was a map, on page 18, of St. Louis which purported to show, and I think did show to a considerable extent, that there is a correlation between the school enrollment of mildly retarded educable children and the existence of poverty.

It showed the proportion of all schoolchildren who are enrolled in special classes for the educable mentally retarded, by census tract.

It showed that the highest concentrations were in areas designated as poverty areas.

The majority of these people, the mildly retarded, don't need specialized facilities for the retarded. They don't need to have a building apart marked "institute for the retarded." They need to have specialized services, from specially trained people, services built into the neighborhood health centers, into the education system, into the social service systems, so that their needs can be met where they naturally come for service.

They do not need to get a big separate installation and a big label "mental retardation" placed on them in that way.

They need to be seen for what they are, if they are indeed mentally retarded, by the people who deal with them, who attempt to assist them professionally with their problems.

Let me digress for a moment and tell you that a recent followup study of the retarded in the public schools of New York City reveals a very interesting thing.

It showed that whereas the enrollment in special classes for the retarded in New York City of Negro children was approximately proportional to the total number of Negro children in the New York public schools, the enrollment of Puerto Rican children in special classes was double and the enrollment of other white children was half, in proportion to their enrollment in the public school system.

What this says is that Puetro Rican children are being identified as mentally retarded under situations that raise grave questions as to whether this is true mental retardation or whether this is the result of their failure to respond to the tests that we give them in a language foreign to them.

Now this issue has become a hot one in Los Angeles recently, because of the large Mexican-American population there, to such an extent that the Los Angeles city schools have forbidden the giving of so-called IQ tests to first and second-graders lest the children get a label that they should not have, of mental retardation.

Now I am saying this to point out that when Mr. Black says clearly "75 percent of the retarded are in the poverty areas" he hasn't distinguished the mildly retarded from the severely and profoundly retarded.

In MR69 there is a map showing distribution, showing the number of identified profound and severely retarded persons in Los Angeles County overlaid with an indication of where the poverty areas are.

I think if you remove the overlay on the poverty areas here and if you take account of the density of population in the tracts which concentrate more in the center of the city, the very few people could look at that map and say, "Oh, well, I can tell from that map where the poverty areas are."

We don't deny that there is some correlation between the conditions of poverty and the conditions of severe mental retardation. There is some correlation because lead poisoning, for example, which is a very devastating cause of severe mental retardation, is more common in dilapidated housing areas than in the suburbs. There are other factors, also. But basically, the distribution of severely and profoundly retarded children and adults is not so very, very different in the different socioeconomic groups, and there is desperate need in all of them.

Now, if Mr. Black only knew it, we in NARC were among the first to point out to the administration back in 1965 and 1966 that the functioning of Public Law 88-164, for the reasons he outlined, was not resulting in facilities for the retarded being built in the poorer parts of town.

This had to do with the matching formula, the low Federal share in urban States, and with the laissez faire dependence on local private initiative, which was stronger in the more privileged areas, and it had to do with the lack of any visible means of supporting the program after it got going.

We have addressed ourselves to this problem in NARC. Mr. Black didn't tell you that half of the staffing grant money that was awarded in mental retardation, went into areas known to have urban and rural poverty.

Your bill addresses itself to this problem. I think I mentioned in my testimony that the bill requires States to give priority attention to the areas of urban and rural poverty. I also mentioned the proposal for increased Federal matching under the construction provisions in title IV of the act.

It should also be pointed out that many of the existing programs—other existing programs—can be brought to bear on the mildly retarded in the poverty area and should be brought to bear.

So this argument seems to me to have been distorted. It is clear that we need to get more facilities for the moderately, severely and profounded retarded in the poverty areas. There is no question about it. Your bill would permit this to be done, would provide incentives for it to be done under a formula grant approach.

Another thing we might mention is that Mr. Black kept saying that the distribution of mental retardation is not equal among the States. If you assume mental retardation is more present in poor States than in wealthy ones, let me point out that the formula for allotting the funds gives attention to that. The per capita income in Mississippi is about half the national average and in Nevada it is about twice the national average.

Fiscal resources of the States are taken into account in the formula for allotting the funds under the present act which would be continued under your bill. I think this is not a good argument for an exclusively project grant approach.

Senator KENNEDY. What about the level and duration of funding under the bill. Do you think it is adequate?

Dr. BOGGS. I would say it is minimal. What we have been getting and are likely to get is less than minimal, however.

Senator KENNEDY. Is there any point in putting in an authorization which is above a realistic level that can be expected for appropriations?

Dr. Boggs. Yes. I think the authorizing legislation should reflect the need realistically, not grandiosely, but realistically. The limits set in Public Law 88-164 could and can be justified.

For 1970 it authorizes $20 million for part B, enough for six or eight facilities. In S. 2846 you ask for $20 million a year for 5 years. If we could achieve this level we could fund one per State or one per 4 million people by 1975 and be at full production in training professionals by 1985.

For 1970, part C construction is authorized at $50 million. This is the annual level that was proposed by the President's Panel in 1963. Allowing for the fact that we have put up less than 100 million Federal dollars in 5 years, for inflation and for population growth, a level of $75 million rising to $200 million just for construction and just for mental retardation is not out of line.

Costs of services quite properly outweight construction. At present the States and counties are putting up more than a billion dollars a year for the care, training, and rehabilitation of the relatively small group—a quarter million—of the retarded who require residential care. If Federal aid is to give the desired lift and new directions to this program, more than token dollars will be needed.

On this basis alone, the $100 million specified for 1971 in S. 2846 is a "barebones" statement of need for the retarded alone. Increases in subsequent years should reflect the expanding attention to needs of the retarded plus a markup, eventually reaching 50 percent, as other developmental disabilities are phased in.

Senator Kennedy. How about duration; is a 5-year authorization too long?

Dr. Boggs. Five years is none too long and 3 years is too short—too short to enable the bureaucratic machinery to revolve and produce results before we have to come back to you again to extend the program.

In my State, we used to have required automobile inspections every 6 months—and a jam-up. The law was changed to require annual inspections. The accident rate wasn't accentuated by the jam-up was eliminated. If Congress wants to get home before election day, it can do so by giving some of these programs less congressional oversight and more time on the road between inspections.

Senator Kennedy. I want to thank you very much, Dr. Boggs. You have covered a number of different areas and it is extremely helpful to us.

Again, thank you very much. You have been a great help to this committee. The testimony you have given will be extremely valuable to us.

Dr. Boggs. Thank you for your kind attention and courtesy and for sponsoring the legislation.

Mr. Hayes. Thank you very much.

Senator Kennedy. Our next witnesses will be Dr. Robert E. Cooke and Dr. Arnold Capute from Johns Hopkins University. Dr. Cooke was trained at Yale in pediatrics and physiology. His first experience with the retarded was in 1944 at the Southberry Training School in Connecticut. He served under President Kennedy on the President's Panel for Mental Retardation, and was a member of the President's Committee on Mental Retardation under President Johnson and

President Nixon. In addition, he was Chairman of the Planning and Steering Committee for the Headstart program. He has two severely retarded children.

Dr. Capute was a practitioner in pediatrics on Long Island before coming to Johns Hopkins. During his practice, he had the opportunity to see the hardships of families with severely retarded children, and he came to Johns Hopkins for special training in this area after many years of private practice.

We want to thank both of you gentlemen for being here today.

STATEMENT OF ROBERT E. COOKE, M.D., PROFESSOR OF PEDIATRICS, THE JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE, AND PEDIATRICIAN IN CHIEF, JOHNS HOPKINS HOSPITAL, BALTIMORE, MD.; ACCOMPANIED BY ARNOLD CAPUTE, M.D., DEPUTY DIRECTOR, JOHN F. KENNEDY INSTITUTE FOR HABILITATION OF THE MENTALLY AND PHYSICALLY HANDICAPPED CHILD, JOHNS HOPKINS UNIVERSITY, BALTIMORE, MD.

Dr. COOKE. Thank you very much, Mr. Chairman. It is a great pleasure and privilege to testify this morning.

I would like to point out that as acting director of the John F. Kennedy Institute for Habilitation of the Mentally and Physically Handicapped Child I have, I think, immediate experience with the problems of the university-affiliated facilities and will address more of my remarks to that problem; but, my remarks are pertinent as far as title I is concerned, also.

It is worth pointing out that the Kennedy Institute which is the university-affiliated arm of the Johns Hopkins Medical Institutions is built in the center of one of the ghettos of Baltimore and does represent an opportunity to provide services to the handicapped who are in addition very impoverished.

I am appearing in support of Senate bill S. 2846, just as I had the pleasure and privilege to appear in support of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963.

As a professor, and as a consultant to the U.S. Public Health Service, and later, as a consultant to the Social and Rehabilitation Services Administration, I have had the opportunity to view the accomplishments of that act.

It led to the creation of mental retardation research centers where concentration on the cause and prevention of serious developmental disabilities, as well as research on diagnosis and treatment, has been carried out.

Since that time, successful work has been carried out on projects such as rubella, and such as the various genetic and chemical abnormalities which produce serious retardation, now called inborn errors of metabolism.

When the previous legislation was passed, there were some 25 serious disorders of unknown cause. It is now known that these are caused by a specific chemical abnormality. Approximately 1 dozen of these can now be treated through chemical, dietary, or other means.

These research centers have given us adequate information to detect the carrier state of serious genetic problems. For example, there is one condition, the Lesch-Nyhan Syndrome, which was described by and named after two physicians in my department.

These doctors have shown the presence of a disturbance in uric acid metabolism, somewhat similar to that producing gout, but, in these cases, associated with a very severe form of retardation, with self-mutilation as one of the most striking symptoms, as shown in these photographs.

(Slides.)

Dr. COOKE. (Describing slides.) To go back just a second, this is a very severely defective child.

This shows self-destruction of the lower lip. The brother of this child had extensive damage to his face because of self-mutilation.

Here is one with damage to the fingers.

This condition is accompanied by a very severe self-destruction tendency as the slides illustrated. These children destroy their own fingers, lips, and other parts of the body with terrible problems for a family to contend with.

The research centers have enabled us to determine the carrier trait of this condition in the female with very simple tissue culture approaches, not unlike those used in the screening of antibiotics.

This makes it possible to carry out very accurate genetic counseling to assist these families in their future lives.

There has been progress on the development of analytical networks through which, essentially, every family with genetic disease of a serious nature may, in some way, be assisted in appropriate diagnosis regardless of their geographic location.

The community service facilities that were described in the original legislation have permitted extensive expansion of services to the retarded.

Workshops have been built; diagnostic and evaluation centers have been created; special schools have been initiated. These advances can be adequately documented by the administrators of the construction program.

The training centers, or university-affiliated facilities have now been developed. Nineteen are in active operation or in the process of construction. These community resources have permitted the development of new community-based service programs in health, in rehabilitation, in day care, and in special education, especially for the younger child.

The existence of community centers for the retarded has provided an opportunity for a private foundation, the Joseph P. Kennedy, Jr., Foundation, to develop a nationwide special Olympics program that has channeled the energies of parents, volunteers, and community workers into permitting the retarded to show what they can do.

The special Olympics program is serving as a motivational "framework" within which physical education, recreation, and sports activities can take place. Specifically, special Olympics (*a*) provides motivation for the initiation of physical education and athletic programs where none exist; (*b*) provides supplementary materials which will aid those currently conducting such programs; (*c*) provides opportunities for athletic competition through local, State, regional, and international special Olympics; (*d*) gives each retarded child a "feeling of belonging" by offering him membership in a national athletic club with membership certificates; periodic newsletters, et cetera; (*e*) instills a "sense of pride" in the retarded child by giving him a chance to win an award be honored at a school assembly, or have his picture in a newspaper—by giving him a chance to know success.

The special Olympics program, for example, is serving an enormous function for the handicapped in cooperation with other governmental and private agencies.

In its first year of operation it involved over 500,000 children in 46 States, and Canada, in eight regional games, 18 statewide programs, and more than 400 local Olympics. Over 40,000 people have become involved as volunteers at local, State, and regional levels most of whom had never before worked with the retarded. Thirteen States have officially recognized these Olympics, thereby allowing the inclusion of special Olympics in hundreds of special school programs.

I would like to introduce for the record, if possible, Mr. Chairman, a script of the film that was developed, which illustrates the accomplishments of this recreation program. I think it would be of interest to show what cooperation between private and public sectors can do, and the opportunity which is given for the development of local community activity. If I could have permission to have that script entered.

Senator **Kennedy**. It will be included in the record.

(The script of the aforementioned film follows:)

A Dream to Grow On

(Chicago Special Olympics Film)

Film opens with long shot of boy running down beach away from camera. Background: Folk singer singing to guitar accompaniment "I Won a Medal."

I won a medal.
It's the first I've ever won.
I won it for running
As fast as I could run.

I'm glad I won my medal—
I'll wear it with pride.
Winning a medal's lots of fun.
But even if I hadn't won
At least I know I tried.
At least I know I tried.

Boy runs to group of children playing on beach with Rafer Johnson. Perhaps they are throwing a ball around the circle or playing tag, et cetera. The boy has brought his Special Olympics Medal to show his friends. Camera on medal.

Narration (Rafer Johnson). Winning an Olympic medal is the greatest thrill in sports. (Film of Rafer Johnson in Olympic decathlon events.) It's the dream of millions of school kids who work and train to run faster. Swim faster. Jump farther or higher. I know it was my dream when I was a kid. And I was lucky there were teachers and coaches to help my dream come true.

(Camera back on kids playing at beach.)

Narration (Rafer Johnson). But you know, there are more than 1 million boys and girls in America who don't know what it means to dream of being a champion; or of making the team. Or of being given a chance to run or swim or jump.

(Camera on one child who has left group and walked down alone towards the ocean.)

Narration (Rafer Johnson). They're the lonely kids you see walking silently along the streets of towns, or standing around watching while the others are playing.

(Camera on faces of children playing. It is now obvious they are mentally retarded.)

NARRATION (Rafer Johnson). They're called mentally retarded. One and one half million of them. They are 3 or 4 years behind in physical development because no one has helped them to catch up. No one has believed in them. And so they don't believe in themselves. When they do try to join in the fun, someone usually takes them by the hand and leads them away. It's too rough, they say. They might hurt themselves. They can't learn the rules.

(Camera on kids throwing the ball with real skill.)

NARRATION (Rafer Johnson). But, you know, when kids like this do get a chance, it's amazing what happens. Brighter eyes—straighter, stronger bodies—keener minds. And they can dream of success . . . of winning a race. Even of winning a medal. (Camera closes in on boy's medal.)

CITY HALL, CHICAGO

NARRATION (Rafer Johnson). Yes, it happened in Chicago on a July day. The day dreams came true for a thousand mentally retarded kids. They traveled by bus and car and plane from 26 States and Canada. One school even brought its own band—and they played for their supper all the way to Chicago. Just as they entertained the people here on the streets of the windy city. These were the lucky ones—kids who had been taught to play. Who had practiced and perfected their skills until they could pass a series of demanding fitness tests. And this was their day. Their own special Olympics.

REGISTRATION

NARRATION (Rafer Johnson). It reminded me of the games at Rome or Tokyo or Mexico City. There was that same sense of excitement and anticipation as the athletes registered at special Olympics headquarters. An Olympic village of their own. It was a chance for the boys and girls to relax . . . to get to know each other before the games began. To swap badges and addresses. There was music and fun and a spotlight of attention and pride on them for the first time in their lives.

Dinner that night was a gala banquet in a hall bright with the special Olympics blue and gold. And after dinner—a magician to mystify and entertain them. A little rock and roll topped off the evening before that good night's sleep in preparation for the demanding day ahead.

SOLDIER FIELD

NARRATION (Rafer Johnson). Soldier Field, the site of many a sporting thrill, is once again prepared for another. Days in advance the field has been carefully worked on to be made ready for the more than 200 separate events to be conducted there. Track and field—swimming—basketball—football—hockey—special clinics and demonstrations—roller skating—ice skating—gymnastics—calisthenics. And not one of these events is out of the reach of a retarded child who has been given a little help in learning how. Who has been told "you can do it." And now the big day dawns. It begins with a special breakfast at the training table. Now the giant buses take the first contingent of athletes to Soldier Field.

ARRIVAL, SOLDIER FIELD

NARRATION (Rafer Johnson). The kids troup into the huge stadium like seasoned performers. It's not at all like the playground back home. But the young athletes take it all in stride. The 50-yard dash or standing broad jump will be just the same here as on that familiar playground. These kids have been given the confidence to know what to do—and how to do it. And they're ready to try—to give it all they have.

PARADE

NARRATION (Rafer Johnson). It starts like all great Olympics, with a parade. Bands and flags, drum majorettes, and more bands, and kids from Canada, Connecticut and California and, of course, from Chicago.

They pass the reviewing stand marching proudly by the Governor and the mayor and the other dignitaries who have come to see them and to cheer them on. Then, out onto the field where soon they will be giving the best they have in them—in the true Olympic spirit.

The coaches are introduced. Olympic athletes of the past—great champions. Tough competitors all of them. Howard Hopalong Cassidy—Heisman trophy winner at Ohio state. Joey Giardello—former middleweight champion of the world. Paul Hornung—one of the all-time greats of the Green Bay Packers—another Heisman trophy winner from Notre Dame. Me, Rafer Johnson, congressman Bob Mathias—two-time Olympic decathlon champion and finally, the chief coach of the special Olympics Apollo 8 Astronaut Jim Lovell.

The flags are up. The Stars and Stripes, the Maple Leaf of Canada.

Mrs. Sargent Shriver, President Kennedy's sister, speaks to the athletes. The Kennedy Foundation along with the Chicago Park Department is making these games possible.

Mrs. SHRIVER. Members of the Clergy, Governor Shapiro, Mayor Daley, President McFetridte, Ladies and Gentlemen, Olympic Athletes.

Just being here today is one of the greatest experiences of my life. I know you all feel the same way about taking part in these Special Olympics. I look forward to a day of tough competition, physical exercise, of learning new skills and of plain good fun. These games are for you to enjoy. There are medals and awards to win, new friendships to be made. The spirit of the Olympics is as much here today in Chicago as it will be next month in Mexico City. I am looking forward to every exciting minute that lies ahead. Good luck to all of you.

NARRATION (Rafer Johnson). The Olympic torch is carried down the track by a proud young runner. The flame is lit. The flame of hope, symbol of all our efforts for the mentally retarded. You will remember it was President Kennedy who said "although children may be the victims of fate, they will not be the victims of our neglect." The special Olympics flag is raised, gold on a field of blue, and the air is filled with balloons, each one carrying the name of one of the young Olympic competitors. And now the games are ready to begin.

There's action all over the field. The 300 yard run—longest race in the special Olympics. But they've learned to pace themselves for the final kick. The finish line seems a mile away. In your hometown there are kids like these who have probably never even run a few feet. But see what love and patient help can do.

There are seven basic events in all. And each boy or girl can enter two. Most of them have been learning and practicing throughout the year. Back home, at school or through their community's recreation department, they have been part of a physical fitness program established by the Kennedy Foundation and the American Association for Health, Physical Education and Recreation. They can qualify for competition in one of five categories depending on their performance. For those who can barely meet the established standards, there is the novice category—then the silver—the gold—and finally, for the most capable of all, the champ. So throughout the special Olympics they'll be competing against kids of the same age whose skills are much like their own. Even the youngest there can make the distance. Watch them go. The incentive is there, and so is the opportunity to win.

The baseball throw. Every throw is carefully measured. Today's winner tosses the ball 178 feet. That's almost good enough for the big leagues. And now the winners receive their honors. Gold, silver and bronze.

The 50-yard dash. Shortest, yet severest test of speed in the special Olympics competition. Only two-tenths of a second separates gold, silver and bronze.

FLASHBACK TO TERRE HAUTE PRACTICE

It's not just luck or accident that wins the medals today. Long hours and days of practice have built up skill and know-how. Volunteers have pitched in to help parents and teachers. It takes patience, but the rewards are so great. Show them the fine points—work with them. Let them practice. Over and over again. This isn't just fun and games. It's a subtle training for life itself. Teach coordination, free the body from clumsiness and uncertainty, and the mind becomes free to learn its other lessons. Facts—skills—citizenship—a job. These hours of physical training are about the most important in his young life. And the medal he wins is only a symbol of his newly won belief in himself.

He's trained hard for this 100-yard swim. It takes real heart and stamina. At the end of the race he finds his reward. How about the swimming program in your town? Does it give the retarded children this chance to learn? This incentive to compete?

CLINICS

Narration (Rafer Johnson). Throughout the day the coaches conduct clinics sharing their skill and experience with these kids who want so badly to learn.

World Champion Gary Erwin dazzles the eye with his grace on the trampoline. It looks easy—but it's not. There are bound to be spills and bruises. But Patience and a helping hand work wonders.

Gymnastics for the girls. These exercises are the most demanding in coordination and timing. They take practice. Someone to say "You can do it" and to be there while they try.

The Chicago Bulls pro basketball team is out in force and the kids learn fast. Break, pivot and shoot. A clean basket. And another. They learn quickly and they don't forget.

Retarded children on roller skates? Why not? It's just a matter of putting wheels on their feet. It comes as natural to them as to all kids. Whoops! A spill—that comes natural, too—but it only hurts for a second.

Now it's time for football practice. Paul Hornung, Hopalong Cassidy, the Notre Dame Varsity, and other football greats. They're all here today to share their knowledge. And the kids respond to their teaching with enthusiasm.

Time our for lunch. Sports whet the appetite. Even a container of milk tastes better when you've run your hardest race and competed for that Olympic medal.

The international floor hockey match between two schools for the retarded. The United States team from Chicago is coached by Stan Mikita of the Black Hawks. The team from Canada is coached by the Toronto Maple Leafs' George Armstrong. He says he's never seen a group of kids play with more heart, yes, they display fierce determination and fine sportsmanship. Good team work. Hard body contact. And with a goal in the final second, the game ends in a tie.

Now the final heat of the 50-yard dash. The long hours of training back home pay off. A silver medal to go with the one for swimming. And a new sense of accomplishment. Can you begin to imagine what this means to him? And to him? But first, someone had to recognize the need, organize a training program, and let the kids stretch themselves beyond anything they'd ever done before.

The high jump. With each successful jump the bar is raised another notch. Up and over. Another notch. I know the kind of determination that takes. Today's champ winner clears the bar at just under 6 feet. Once he's accomplished this, he'll be ready to tackle almost anything.

In the late afternoon as shadows fall across the stadium, the young competitors press on in hopes of winning the cherished prize. It's the kind of thing other kids may take for granted, but until now retarded children have never been counted in. The medals are not just for them. But for all the teachers and volunteers and parents whose faith has made it possible.

A parent's pride matches the joy of his child. A whole new world of success has opened up for all of them.

And that's what these Olympic games are all about. A taste of success, where before there was only failure. A sense of confidence in a youngster who has known only frustration. And even those who have not won, will return home knowing that they tried. Throughout the year, they'll be able to practice and improve, and next time they'll be ready to try even harded.

(PARADE)

Narration (Rafer Johnson). The last event has ended. The final race is run. It's been a long day under the hot sun. But a day they'll always remember. Back onto the field they march for the final special Olympics parade. Now in a large circle of friendship, they join in the Olympics traditional Auld Lang Syne saying, "till we meet again" to the new friends they've made, to the competitors they've come to know and respect, through sharing the high adventure of giving their best.

Health, fitness, competition, fun—sure. The Special Olympics has all these and more. But it's that seed of success that counts the most. A little seed, maybe. And one that needs much nurturing and care. But once planted, it will grow. Success will build on success. First on the playing field, because that's where it comes easiest and most naturally. Then at home. At school. And later on in the adult world.

Is there a child in your life, in your home town, who is standing on the sidelines just watching the others? Take him by the hand, give him the chance to run his race. To win his prize. Give him an Olympic-size dream. Give him a dream to grow on.

(Back to Rafer Johnson and end with "I Can Do It.")

Dr. COOKE. I would like to indicate that considerable thought and wisdom have gone into the writing of this legislation. It is certainly wise to broaden the mission of the original Facilities Construction Act from mental retardation alone to developmental disabilities, including cerebral palsy, epilepsy, neurological impairments, sensory defects, or other chronic, physical, or mental impairments originating during childhood.

These conditions have a similar causation. They originate from genetic abnormalities, from metabolic disturbances, from defects acquired before or during the birth process and in subsequent years.

In addition, they require, for correction or amelioration, very similar services such as appropriate psychological diagnosis, neurological services, physical therapy, and special education. I think we will be able to demonstrate this very clearly to you today.

Title I has my wholehearted support. The proposal, I believe, will effect a consolidation of services which have been too long scattered and separated on a basis of disease entities which are not truly separable. It will permit States to plan, in a coordinated fashion with adaptability and flexibility, proper programs for the whole range of the handicapped, rather than for only one or two groups.

This, then, will result in a significantly more economical use of funds so that complete treatment and evaluation facilities for each of the disease categories will not have to be developed; rather, joint usage will be required.

These community developmental disability centers will be manned by teams of physicians, such as pediatricians, neurologists, and psychiatrists; of social workers, nurses, rehabilitation specialists, and educators. How will these teams be made up? How will the members be trained? How will they be constantly upgraded in the care of patients? How will various team members properly understand their own role in relation to the other members of the team?

It is a well-known fact that there are three major steps in the training process: (1) Recruitment through the creation of interest in a field, (2) the installation of theoretical information, (3) in-depth practice. The first step must be carried out with young students before a career choice is made.

The only plactical way that this can be done is through universities enlisting students on a part-time basis in combined academic and service activities. Theory during the training must be imparted by people of academic stature who can appeal to the intellect of the trainees. In-depth practice must be given with team approaches that serve as models for future operations.

It is, therefore, completely reasonable that this legislation have, as an essential component, title II, entitled amendments to part B of the Mental Retardation Facilities Construction Act. If title II is to be approved, there are two major questions which must be answered: Why should university-affiliated facilities for the mentally retarded be training centers for personnel who will man the community developmental disability activities; and, why should the training that is to be given at the university-affiliated facilities be interdisciplinary in nature?

I feel I can speak with some authority on these two issues. Johns Hopkins has had a university-affiliated facility in active operation since 1967 and I am presently acting director, in addition to my other duties as chairman of the Department of Pediatrics. What we are doing is comparable to that of actual programs or anticipated programs in the 18 other centers, even though there may be some very worthwhile differences.

Therefore, I would like to speak from our own experience at The John F. Kennedy Institute for Habilitation of the Mentally and Physically Handicapped Child and use it as a model for other university-affiliated facilities.

From the standpoint of providing service to the handicapped, we have cared for about 400 children as inpatients and at least double that amount on an ambulatory basis. Each case is handled in the following way. Prior to admission, the child's reports are collected from the referring agencies.

Physicians, psychologists, other hospitals, even school systems provide us with as much information as possible on the patient's particular kind of disability. If the Admission and Discharge Committee believes that the Kennedy Institute can be helpful to the patient and to his family, and, if the case is of value from the standpoint of training personnel, the case will be accepted.

On admission, the child and his family are seen by representatives of the two major divisions—the biomedical and the behavioral—each equipped with adequate screening tools for the detection of defects pertinent to each of the particular disciplines of the Kennedy Institute. For example, information is obtained that is useful to ascertain the importance of social service, of psychology, of nursing, of occupational therapy, and of physical therapy to the particular patient so that a tentative diagnostic and treatment pathway can be obtained which is of optimal value to the patient and the family without marked duplication of services and unnecessary examination.

I have seen facilities where staff have not been developed in such an interdisciplinary manner and where every child is subjected to the same examination. In such a setting, I have seen a child receive an extensive speech and hearing examination, even though his mental age is only 2 or 3 months.

At the Kennedy Institute, the disciplines that can contribute to the particular case study the patient for a period of days. They then pool and compare their information in a major habilitation conference and the patient is assigned to a subsequent major discipline for therapeutic approaches which are monitored by other disciplines to ascertain the degree of improvement in relation to expectation. After a period of weeks, when specific therapeutic measures have been worked out, the family and representatives of community resources, such as community schools, social work programs, and day care facilities are brought in to learn the therapeutic approaches which can be applied specifically for that child in his home environment.

The Kennedy Institute has carried out a very substantial training program. Formal lectures and conferences are held regularly throughout each week rather than on a monthly or yearly schedule, as was the situation several years ago in the usual university environment.

In the past year alone, we have trained over 175 nursing students, over 50 students in physical therapy, five psychiatrists, four psychologists, 17 special education teachers, nine social work students, 30 medical students, 24 residents in pediatrics, five full-time pediatric fellows, and almost 75 students in speech and hearing.

In addition, extensive course work has been given for clinical pathologists in genetic and biochemical detection; for graduate students in occupational therapy, rehabilitation, and for specialists in library sciences.

The number alone do not express the contributions which the university-affiliated facility has made from the training point of view. Each discipline has had intensive technical training in its own area; but, in addition, as an example, the physical therapist has learned how his or her activities can complement the activities of the psychologist, the behavior modification specialist, the neurologist, and so on.

In this way, gains made by one therapist are not eradicated by the efforts of another. For instance, a child who is undergoing conditioning procedures for improved socialization—so that the family can live peacefully while the child is in the home—presents a particular problem if the personnel carrying out physical therapy of that child do not follow similar principles of behavior modification and reward.

In the process of learning, the psychologist learns the role of the speech therapist in the treatment of the handicapped so that, if he becomes the primary referral source, as may be the case in the community, he can wisely choose the appropriate specialist. The pediatrician must learn the contributions of the educator. Likewise, if a retarded child is brought to a special educator, he must have an appreciation of the disciplines to be involved.

The Kennedy Institute's impact on student attitude at present is in contrast to the experience of an instructor in public health after conducting field trips for medical students to an oversized residential facility for the retarded.

I quote from this paper:

> Part of the shock of students who visit this facility may be related to the experience of being confronted with so many problems at once. The physician is confident that he has certain specific measures to offer an individual patient in discomfort: when the student is faced with a large number in severe distress, he is extremely uncomfortable merely because of the numbers. When students are interested in such a facility, they go largely as spectators rather than as physicians.

By comparison, over 25 percent of the students at Johns Hopkins, in the course of their medical school experience, choose work in the Kennedy Institute in preference to other exciting experiences in the care of acutely-ill patients or patients with other diseases than those with chronic disability.

In the research area, major emphasis has been on the development of new treatment strategies, new medical rehabilitation approaches, and new forms of special education with careful comparisons of treatment benefits. For example, we are interested in studying, in a given patient, whether or not behavior modification will produce greater social benefit or greater educatonal benefit than more conventional approaches.

One study of particular interest and importance to education is that of the talking typewriter. This is an instrument that costs approximately $40,000 with several thousand dollars annually for soft ware.

We know of one school system which has purchased about $2 million worth of these.

A controlled experiment comparing this form of remedial reading for the handicapped with other forms has indicated the advantage, in the pilot program at least, of a human teacher over the machine—and at approximately one-fifth of the cost. Other comparative treatment programs are underway which could have equally startling results.

The university-affiliated facilities have had an even more important role than simply these program objectives. Essentially, they have been unifiers of the university. They are a kind of mini-university: a meeting ground, a point of convergence for the medical sciences, the behavioral sciences, and the educational sciences. Unless these three areas concentrate their efforts in a coordinated manner, relatively little gain will be obtained by each carrying out his own independent efforts.

The university-affiliated facility is a meeting ground with a common concern for human beings in need of assistance. This need is strong motivation to effect cooperative and coordinated work. In this regard, the university-affiliated facilities have served as the major center of interest for the mentally and physically handicapped child in the academic community and in the general community along with the Kennedy Foundation and the National Association for Retarded Children, as Government over the last 4 years has demonstrated a dwindling concern for the well-being of the retarded.

The university-affiliated facilities are also proving to be a focal point for educational approaches to difficult chronic problems in our society. They are also serving as proving grounds for the training of individuals in team practice.

Despite the serious financial limitations at the present time on medical institutions, the Johns Hopkins University as a private institution, though feeling very seriously the cutbacks in support by the present administration, is still giving considerable financial support to the Kennedy Institute. In 1 year alone, the medical institutions have contributed over one-quarter of a million dollars in in-kind services and dollars to that facility.

More importantly even than this strengthening of internal university interest is the role that the university-affiliated facility is playing as a link to the community. It is essentially the bridge between the university academicians, and the community practitioners and families. It is a presentation of academics with relevance.

First, it is a training resource for personnel from community programs, for public health nurses, and for black students in special education at Coppin State College who will provide the major special education resource to the city of Baltimore.

It is a public information facility where activities for the retarded can be centralized, a meeting ground for parents' groups, and a center for State program planning. It is a training facility for the community with Neighborhood Youth Corps working on weekends and through the summer. It is the focus for a new careers program where poor people of Baltimore are given the opportunity to enter the health professions.

These people are guided up a career ladder beginning as trainees to be a child life manager who is responsible for assisting the retarded in social skills. The next step for such workers is specialization in areas such as occupational therapy and physical therapy; or, working as psychology aides; or, in obtaining associate degrees through community colleges. Further educational progress may involve degree-granting colleges, and, eventually, professional schools.

It is a center for the training of day-care workers and for pediatricians who come from practice to learn how they can better manage the retarded. It is a summer school for teachers who wish to learn more about the biomedical as well as educational aspects of the handicapped.

And finally, it is a service facility for the community where children with severe educational problems may be brought to our school on a daily basis; where cerebral palsy clinics of charitable groups are conducted; and where the cleft palate clinic of the Johns Hopkins Hospital meets as well as the child neurology clinics. In essence, it is a court of last resort for families seeking the most advanced medical, behavioral, and educational information for their child.

Our role, then, as we conceive it, is to develop new techniques of screening, new approaches to diagnosis, new methods of treatment, new ways to family education, new procedures in genetic counseling, new careers for personnel, and new disciplines to assist the retarded and handicapped. I believe the university affiliated facilities are succeeding in this role.

The second question which I raised is why should training be interdisciplinary? What are the advantages of this seemingly expensive approach? Actually, the advantages are largely in the greater economy in the use of resources—for the family, patient, and community.

It is to assure that there is greater efficiency in assisting the child. Interdesciplinary means that one discipline must learn how to use, to a degree, the tools of another discipline, and work with that other discipline to develop some optimal path for the treatment of the child.

We, in no way, mean to disparage the efforts of others in training, but if one analyzes the experiences which a trainee at the Kennedy Institute receives in psychology, for example, one can see that he learns the role of the neurologist, of the psychiatrist, of the educator, and the abilities and limitations of the physical therapist. He develops a realistic appreciation of what can and cannot be accomplished.

This is absolutely essential since so many of the handicapped reach treatment facilities by way of singular members of the scattered health team. For example, a teacher may be the major source of referral, or, perhaps, a public health nurse.

Let me illustrate some of the problems associated with this approach. An 18-year-old child, the daughter of an important family in this country, is being admitted to the Kennedy Institute this week. This child has a severe hearing disorder as well as some neurologic dysfunction. She was subjected to speech therapy for 8½ years despite the fact that the major deficiencies are in the prevocational and intellectual areas.

Not only was this a waste of financial and human resources, but valuable time has been lost that could have been put to far better use if more realistic expectations on the part of the people making the earlier referrals had been carried out.

What, then, should these centers be? They must be administered in a way that permits them to interrelate as much as possible with the community developmental disability facilities. They must be consultation centers for the satellite groups in the community which will carry out a large part of the service programs for the handicapped.

They must be community training centers which train personnel for the satellite units and provide subsequent inservice training. They must be community research centers that can develop the essentials of better treatment and pass on this information to community programs for immediate application.

From a cost-benefit standpoint, there is impressive evidence of what can be accomplished for the handicapped through these university-affiliated facilities. Yet, for those members of our society who are skeptical of the value of any efforts made for the handicapped, it is appropriate to point out what may be accomplished in terms of real benefit for the normal child.

Historically, medicine has learned a great deal of what is important for the normal from the study of disease. For example, the study of diabetes has contributed a great deal of information concerning normal carbohydrate metabolism. The study of cretinism, a bizarre form of retardation studied many years ago in Switzerland, demonstrated the role of the thyroid gland in normal people.

The study of inborn errors of metabolism has provided information on the normal chemical pathways of the body. The study of Mongolism, or Down's Syndrome, I believe, will contribute very significantly to our understanding of the aging process. Likewise, in the study of learning problems of the handicapped, much information can be obtained which will be valuable in understanding the normal child.

For example, an appreciation of the existence of individual variation in learning abilities is absolutely critical to the most effective use of our educational resources. Individual variation is a concept which has not been fully appreciated by education and which comes from the study of individuals with disability.

Conservative estimates of so-called normal schoolchildren with unusual profiles of intellectual capabilities vary from 15 to 25 percent. Optimal education of these normal children requires individual teaching methods—the development of what might be called prescription teaching—to exploit the child's areas of strength and to attempt to bring his areas of weakness up to a normal level.

It is essential that adequate scientific epidemiologic approaches in the description of learning disabilities be developed so that communities can plan and experiment with different types of resource allocations which ensure that our educational dollar buys a maximum education for all pupils over the spectrum of abilities ranging from the mentally handicapped to the child who is quite intelligent but has only specific learning disabilities.

Another example is in the area of psychiatry. The study of the basis for the strength of a family facing severe adversity can lead to improved ways of assisting the normal family to be prepared for hardship. Likewise, in the area of behavior modification, the use of conditioning procedures to remove unacceptable behavior has obvious application for normal child-rearing practices in determining the importance of rewards.

I should like to make sure that, within the legislative history of this bill, there is proper concern for the financial support of these centers. The construction funds should be allocated in a way that will permit optimal support of community resources. This will entail a careful programing to ensure that there is adequate geographical distribution of the university-affiliated facilities.

Facilities must be built in locations and at university centers which will provide maximum support for regional or State community programs. In addition, the funds which are authorized for support are absolutely minimal and are a long way from being optimal.

I believe that the support of these facilities must be in four categories.

First, sustained dollar support over a period of 5 to 10 years for direct cost and administration. This would provide for core activities to insure that there is continuity of staff from year to year which can lead to progressive improvement in programs.

Second, there should be dollar support for specific programs which comes from established agencies awarding funds in competition with other training, demonstration, and research activities. It is extremely important to assure that these centers are not excluded from such support programs because of the core support to which I referred.

Third, support of indirect costs must be adequate to insure universities and their affiliated facilities are not depleted of resources in the process of maintaining the high cost of the programs I have indicated.

Fourth, there must be money for development so that emphasis can be placed on new methods of operation. I believe these funds should come from the efforts of the university-affiliated centers themselves through the recovery of monies for services performed, and should be used only for professional research and teaching just as universities use new funds to develop new programs. Such a mechanism will provide incentive for the acquisition of appropriate funds for services rendered.

These four support efforts must be for all elements of the center, not just the biomedical, or the educational, so that maximum balance can be obtained and maximum flexibility in the use of funds can be made possible. At the present time, there is a very serious imbalance which compromises the interdisciplinary approach.

Either the biomedical support in some facilities is grossly underdeveloped and undersupported, or the educational support is seriously compromised, as is the situation in most of the facilities. Indeed, what has developed is competition instead of cooperation in acquiring funds for the major areas of the program and this competition has seriously limited development.

Methods must be found to reward joint activities so that divisions with educational responsibility and divisions with biomedical responsibility can be encouraged to work together. Likewise, centers with major emphasis on one or the other can also be encouraged to cooperate.

In conclusion then, I feel this legislation has great merit. Is seems that the only way community programs, which are demanded by society, can be effectively implemented and improved on a year-to-year basis is through the parallel development of the university-affiliated facilities.

As a way of illustrating the particular accomplishments in a somewhat graphic manner, I have asked some of the staff of the Kennedy

Institute to accompany me to present, very briefly, a few case examples of the kind of service programs upon which the framework of training and research are built.

Accompanying me is Dr. Arnold Capute, who is deputy director of the Kennedy Institute, and he will present these cases. I appreciate the opportunity to appear before the committee and I hope that the legislation will be successfully enacted.

Senator, we have some video tape and some parents have been good enough to bring the children in so that we may have some opportunity to see the contrast between the way these children were before they came to the Kennedy Institute and their present behavior.

STATEMENT OF ARNOLD CAPUTE, M.D., DEPUTY DIRECTOR, JOHN F. KENNEDY INSTITUTE FOR HABILITATION OF THE MENTALLY AND PHYSICALLY HANDICAPPED CHILD, JOHNS HOPKINS UNIVERSITY, BALTIMORE, MD.

Dr. CAPUTE. We have three cases from the John F. Kennedy Institute depicting developmental disabilities. The first to be shown is little Cynthia Evens, a 5-year-old female, first admitted to Kennedy Institute at 3½ years of age. The developmental disability was absence of the sacrum and lower lumbar spine.

Associated with this she had, shriveled legs and when admitted Cynthia walked on her hands which was felt esthetically not acceptable. It was a long drawnout process for the psychiatrist, pediatrician, the physicians of the community, and others who had shared this responsibility, for the care of the child, to have a conference with the family.

When I was in medical school I would have seen this child with one disorder, mainly physical, with a one channel approach, orthopedics. She would have had occupational therapy and physical therapy under the supervision of an orthopedic surgeon.

Today, we know that developmental disorders frequently involve more than one system. When Cynthia was admitted to the Kennedy Institute, the main problem initially was the lower extremities. The decision was that her legs should be amputated and that she be fitted with a bucket-type prosthesis having two artificial lower extremities.

The parents were not convinced of this need. Since many of the disciplines working with Cynthia, were running into a stone wall, we recommended that she see Dr. Aikens in Detroit, who performed several of the original operations (less than eight have been done in this country). We welcomed the Evens family not only to speak to Dr. Aikens, but to see other children who had this operation a year or two previously and to see how they had progressed.

This trip greatly assisted the family in arriving at the decision that the child should be operated.

On admission we also noted that Cynthia lacked the necessary nerve supply to the urinary bladder. For children to attend special education classes in Maryland, they should be dry. The family went along with our recommendation; the urinary diversion procedure was perform and Cynthia now has a urinal bag which she empties periodically unassisted.

While the mother looked upon the lower extremities and urinary bladder as the most important habilitation procedures, the Kennedy staff felt the learning disorder discovered upon admission, was to be the most important aspect of her habilitation. It is this type of learning disability which hopefully through institutions like the university-affilated centers, with pediatricians working with psychologists and educators, will devise a teaching method to greatly improve this developmental disability by special teaching techniques. This is a bright little girl with a normal IQ however she does have a scattering of mental abilities, which is commonly associated with learning disability. I would like to go on with the pictures if I may. They are most dramatic.

Film commentary: Here she is at the beginning. This is the way she walked around. Born with congenital absence of lower lumbar spine below the level of L–2 and absence of the sacrum. She has very small deformed legs with muscle wasting. She cannot bear any weight on her legs and gets around by walking on her hands in this manner. You see her attempt at walking. She does not bear weight on her legs, although she can move one in front of the other. Neither leg can be straightened more than seen in this picture.

Several years of attempts at therapy have been tried. With braces, crutches, various types of apparatus, but she has still been unable to use her legs to walk. She gets around the house on her hands, gets in and out of the wheelchair herself. At the age of 4 years and 7 months, both legs were amputated just below the hip joint. She was then fitted with a bucket type prosthesis. She carries all her weight now at the top of the bucket, which rests on her chest wall. These legs have freely moving hip joints and freely moving knee joints to allow her to sit in as normal fashion as possible.

When standing and walking the knees and hips are maintained in a straight position through the efforts of the child putting the weight on her feet in the proper manner. She has been trained to do this and has done very well. This is an adult size chair she has just gotten into. She managed to put her crutches on the side where she can easily retrieve them when she is ready to get up.

She is able to completely remove her clothing, get out of her bucket prosthesis and get into bed, which she does daily at home, she completely takes care of dressing and undressing and getting in and out of bed.

There is the urinal bag.

You can now see the top of the bucket prosthesis which she slips into. The prosthesis is held in place with two shoulder straps which she is now removing. Due to lack of bladder control, she has had a procedure for an ileal loop. She now removes the bag which holds the urine from inside her prosthesis. She will now get out of the prosthesis and into bed.

This demonstration was held in one of our three apartments where parents come to observe the disciplines working with the child.

She can then get out of bed and completely dress herself. She is able to manage her own bag, take herself to the bathroom, open and drain the bag and replace it correctly.

Senator KENNEDY. Doctor, I just wish my children could see that.

Dr. COOKE. We hope we can put together a film sometime that will illustrate this for the general public. I think it is really remarkable.

Dr. CAPUTE. Here you have seen a child who initially was managed by occupational therapy, physical therapy, orthopedics and soon after social service, psychiatry and pediatrics were brought into the picture; after the lower extremities were amputated and the bucket prosthesis applied, occupational and physical therapy were once again brought back. She has worked with this prosthesis for the past 2½ months and you can see how well she is doing. Now she is almost 6 years of age and approaching the school years. The learning disability will receive guidance by the educator.

Dr. CAPUTE. Did you want to say anything, Mr. and Mrs. Evens?

Mrs. EVENS. Not anything particular except how much we appreciate Kennedy and what they have done for us.

Dr. CAPUTE. Any questions at all?

The next case presented is Vicky Linck. A tragedy occurred to Vicky in May of 1968, at which time she was in an auto accident and sustained injury to the brain.

Commentary. July 15, 1968, Vicky is 8½ years old. She was admitted to the Johns Hopkins University on May 10, after an automobile accident.

This was May 1968. At 8½ years of age she was in an automobile accident. Vicky came to the Institute 2 months after a severe automobile accident. One of the values of the UAF's is providing a facility where experts can be called in on the initial phase. About a month after the accident, while she suffered from a severe neurological deficit and her condition was stabilizing, the occupational therapist and physical therapist and pediatrician from the Kennedy Institute were asked to treat Vicky, to initiate therapy and to make preparations for her transfer to the Kennedy Institute for further habilitation.

She was neurologically impaired to the point where she had little use of the four extremities. Her handicaps have markedly improved with the invaluable assistance of the occupational and physical therapists.

Accompanying her physical disability was mental impairment. She is now functioning in the high educable range but with some scattering of her mental abilities which indicates a learning disability. After the remedying of the physical disability an educational profile was worked out. She was given 1 to 1 instruction by the educators on an inpatient basis and soon was transferred to the outpatient special education school at the Kennedy Institute. Here you see Vicky jumping rope and here you see demonstrations of 1 to 1 teaching. Subsequently, she was put in a group as noted in the audiovisual taping. As of now her IQ in in the 80 range (dull-normal) and her speech has improved considerably. The habilitation procedures were carried out by the various disciplines. Hearing and Speech worked with Vicky to improve her with her speech and language disabilities.

Senator KENNEDY. How do you like school?

VICKY LINCK. It is all right.

Dr. CAPUTE. The next patient is Johnny Sarsfield, approximately 10 years old, a boy, who came to the Kennedy Institute at age 7 years, 5 months, with diagnosis ranging from early childhood schizophrenia, 'infantile autism," to profound mental retardation. Johnny was seen by the various disciplines and was felt to be profoundly retarded.

The major manager in his case was the behavioral therapist (psychologist). Johnny came to us with three main problems. One, antisocial behavior, manifested by chin banging to the point where he would lacerate his chin and he was a head banger. He could not function along with his peers because the school from which he came could not tolerate his type of behavior.

The other problem was developing self-help skills. At Hopkins we also remember the word "TED," toileting, eating and dressing. We always phase in on these three things. Most important is social communication. This was a noncommunicating child who did not talk. The psychologists, (behavioral therapist) took him in hand and along with the multidiscipline approach set up prescriptions for nursing, hearing and speech pediatrics and the other disciplines to work with John.

We will show the movies now to depict what accomplishments have been made. At the present time he has been enrolled in a school in Montgomery County in a trainable class.

(Film)

Here is Johnny initially. You see him banging his chin. He has a scar, evidence of trauma. Initially he was taught imitative speech. Now he speaks spontaneously in a functional manner.

It is important for these children to make their wants known, so that they can interact with the environment and develop to their maximum. In other words, if he didn't talk, he would be totally ignored.

Dr. **Cooke**. He is being conditioned to respond for each appropriate bit of speech. So he learns words. These are essentially reinforced. This is the enforcement. We didn't have much therapy there. This is at the time of discharge from the Institute.

This is a child with utterly no speech whatsoever.

Mr. **Sarsfield** (father). I think it might be well to point out that up until the time that Johnny was 7 years of age my wife and I had tried desperately to teach him ourselves. He had been in a 3-year program in a private school in Washington. He did not qualify for the school that he is in right now in Montgomery County; he was functioning at too low a level. In May of 1968 he was admitted to the Kennedy Institute and was discharged in August of 1969. In that short period of time he has developed to the point where now he is qualified to enter the school and is a more functioning member of the family. I think that this little child represents the light that President Kennedy spoke of, lighting the darkness with one candle, because we see here this child is living evidence of coming from a nonfunctioning human being to what he is today, and will continue to develop.

The young man you saw working with him is learning at the same time. That was Dick Blair. All of these men have been trained to do what they have done to John. But in doing this they have so much reinforced themselves and they themselves will go out and spread their techniques to other people and other educators. It will then be a foundation by which many other children like Johnny can be helped.

We would like to thank the Kennedy Institute, Senator, you and your committee, and we sincerely hope that the fund will be made available to make more institutes such as the one in Baltimore available to other people throughout the country. Thank you very much.

Dr. Cooke. Mr. Chairman, that completes our testimony. We are very appreciative for the opportunity to appear here. I am very grateful to the families who have come this morning.

Senator Kennedy. Dr. Cooke, I think there is very little to ask you after your very impressive formal testimony and your splendid and moving case presentations. In your formal testimony you have given what so many of us in the Congress have asked for in the past—an evaluation of the program. You touched on a large number of areas in which I was interested, and you told us how the university-affiliated centers are helping the children to help themselves. There is very little that can be added to the eloquent testimony of the youngsters who appeared before us today.

There is perhaps one final question, and that concerns the level of funding of the UAF program. Based upon your background, your knowledge of the potential of other universities around the country to develop these programs, the interests they have, and the cost of doing so, do you have any judgment as to the funding levels that are recommended in this legislation?

Dr. Cooke. I think the funding levels are absolutely at the lowest possible level compatible with a construction program that will have real impact throughout the country. I think it is anything but extravagant from the standpoint of the support of the university-affiliated facilities. I do seriously wonder whether or not the operational support is adequate. I believe that it is difficult to mount a program for a university-affiliated facility comparable to what we are trying to do at Hopkins for less than $2 million a year, per center.

If one does the arithmetic, the amount of money that is available is very grossly inadequate. Now what is possible, of course, is the supplementation from other programs, sources, training funds in various disciplines, but I do believe the whole support is very much limited and should be increased if possible. Of course, there is a tooling up period for the other centers during which relatively little in the way of operational monies are needed.

But the four points which I made as to the various ways of funding, I would hope could be implemented in some way. There is more support needed and it has to be substantial. There ought to be funds available from other programs for training, research and demonstration open to these centers on a competitive basis, on a project basis essentially.

There needs to be adequate support of the indirect cost and there should be an opportunity for these centers to, in a sense, capture funds in a service activity such as providing services to the States. At the present time, at the Kennedy Institute, every penny that we take in goes to reduce our grant from the Federal Government so there is absolutely no gain. We just simply run in place as far as any additional funds for development is concerned.

Senator Kennedy. Would you explain that please?

Dr. Cooke. Yes. We have a grant from the Children's Bureau that supports the service activities and training activities. If we take in approximately $350,000 in income from services rendered such as those paid for by Blue Cross and Blue Shield, we receive money from under title XIX for the care of indigent patients, we receive money from the State Crippled Children's programs, making up the $350,000. Every penny of that $350,000 returns to the Federal Government to reduce the size of our grant so that we have no way to have any kind of development fund whatsoever for the improvement of programs.

That, I think, is a situation which ought to be rectified in the future. I think some development moneys are needed and if there is income, some of that, at least, ought to be used for professional training and research, just as it is in most university medical centers.

Senator Kennedy. I don't know whether you are familiar with Mr. Black's comments yesterday on behalf of the Administration. Is there anything in his proposal you would like to discuss, particularly as it relates to the university-affiliated centers?

Dr. Cooke. As far as title I is concerned, I really agree completely with what Mrs. Boggs has said. I think there is a belief that the general programs of health care, for example, can meet the problems of the retarded, the regional medical programs. It has been my own experience in working with these that emphasis on the killing diseases—heart disease, cancer, stroke—the killing disorders, will literally overwhelm any programs for the mentally retarded where this is not really in the power structure of medicine and, for that reason, it is terribly important that specific categories of support be retained.

Furthermore, as regards the university-affiliated facilities, I don't care what program is going to be mounted of a service type, trained personnel will have to be available and they are very, very inadequately trained and in very short supply at the present time. So, without the university-affiliated facilities I can't see where the adequately trained personnel are going to come from to even meet the service programs which the administration says it is coming out with.

So that I think these are an essential part of any of the Government programs, even the limited ones of the administration.

Senator Kennedy. Dr. Capute, would you like to add any comments?

Dr. Capute. No, I think Dr. Cooke has summarized it very well.

Senator Kennedy. Let me commend you both for your testimony. I am really heartsick that the other members of the committee did not hear it. I don't think any of us would have any problem at all with any of this legislation if we all could hear and see what we saw and heard this morning. We will try to carry this message to them and do the best we can. Thank you very much, gentlemen.

Dr. Cooke. Thank you.

(The prepared statement of Dr. Cooke follows:)

Prepared Statement of Dr. Robert E. Cooke, Professor of Pediatrics at The Johns Hopkins University School of Medicine, Baltimore, Md.

Mr. Chairman, Senator Kennedy, members of the Senate Subcommittee: I am Dr. Robert E. Cooke, Professor of Pediatrics at the Johns Hopkins University School of Medicine; Pediatrician-in-Chief, The Johns Hopkins Hospital; and, presently Acting Director of The John F. Kennedy Institute for Habilitation of the Mentally and Physically Handicapped Child. I was a member of the President's Panel on Mental Retardation under President John F. Kennedy; subsequently, I was a member of the President's Committee on Mental Retardation under President Lyndon Johnson; and, until very recently, a member of the same Committee under President Richard Nixon. I am the father of two severely retarded children, one of whom died three years ago, at the age of 17, still unable to walk adequately or talk at that time.

I am appearing in support of Senate Bill S. 2846, just as I had the pleasure and privilege to appear in support of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963. As a professor, and as a consultant to the United States Public Health Service, and later, as a consultant to the Social and Rehabilitation Services Administration, I have had the opportunity to view the accomplishments of that act. It led to the creation of mental retardation research centers where concentration on the cause and prevention of serious developmental disabilities, as well as research on diagnosis and treatment, has been carried out.

Since that time, successful work has been carried out on projects such as rubella, and such as the various genetic and chemical abnormalities which produce serious retardation, now called inborn errors of metabolism.

When the previous legislation was passed, there were some 25 serious disorders of unknown cause. It is now known that these are caused by a specific chemical abnormality. Approximately one dozen of these can now be treated through chemical, dietary, or other means.

These research centers have given us adequate information to detect the carrier state of serious genetic problems. For example, there is one condition, the Lesch-Nyhan Syndrome, which was described by and named after two physicians in my department. These doctors have shown the presence of a disturbance in uric acid metabolism, somewhat similar to that producing gout, but, in these cases, associated with a very severe from of retardation, with self-mutilation as one of the most striking symptoms, as shown in these photographs. It is now possible to determine the carrier trait of this condition in the female with relatively simple tissue culture approaches, not unlike those used in the screening of antibiotics.

There has been progress on the development of analytical networks through which, essentially, every family with genetic disease of a serious nature may, in some way, be assisted in appropriate diagnosis regardless of their geographic location.

The community service facilities that were described in the original legislation have permitted extensive expansion of services to the retarded. Workshops have been built; diagnostic and evaluation centers have been created; special schools have been initiated. These advances can be adequately documented by the administrators of the construction program. The training centers, or university-affiliated facilities have now been developed. Nineteen are in active operation or in the process of construction. These community resources have permitted the development of new community-based service programs in health, in rehabilitation, in day care, and in special education, especially for the younger child.

The existence of community centers for the retarded has provided an opportunity for a private foundation, the Joseph P. Kennedy, Jr. Foundation, to develop a nationwide Special Olympics program that has channeled the energies of parents, volunteers, and community workers into permitting the retarded to show what they can do.

The Special Olympics program is serving as a motivational "framework" within which physical education, recreation, and sports activities can take place. Specifically, Special Olympics (a) provides motivation for the initiation of physical education and athletic programs where none exist; (b) provides supplementary materials which will aid those currently conducting such programs; (c) provides opportunities for athletic competition through local, state, regional, and international Special Olympics; (d) gives each retarded child a "feeling of belonging" by offering him membership in a national athletic club with membership certificates; periodic newsletters, etc; (e) instills a "sense of pride" in the retarded child by giving him a chance to win an award, be honored at a school assembly, or have his picture in a newspaper . . . by giving him a chance to know success.

In its first year of operation, Special Olympics (1) involved over 500,000 children in 46 states and Canada, in eight regional games, 18 statewide programs, and more than 400 local olympics; (2) involved over 40,000 volunteers at local, state, and regional levels—most of whom had never before worked with the retarded; (3) received official endorsements of the governments of 13 states, thereby allowing the inclusion of Special Olympics in hundreds of special school programs.

One of the best ways to appreciate what can be accomplished is to show the film made on this recreation program. Time will not permit this but I would like to ask that the script of the film, "A Dream to Grow On," be included in the record.

I would like to indicate that considerable thought and wisdom have gone in to the writing of this legislation. It is certainly wise to broaden the mission of the original facilities construction act from mental retardation alone to developmental disabilities, including cerebral palsy, epilepsy, neurological impairments, sensory defects, or other chronic, physical, or mental impairmants originating during childhood. These conditions have a similar causation. They originate from genetic abnormalities, from metabolic disturbances, from defects acquired before or during the birth process and in subsequent years. In addition, they require, for correction or amelioration, very similar services such as appropriate psychological diagnosis, neurological services, physical therapy, and special education.

Title I has my wholehearted support. The proposal, I believe, will effect a consolidation of services which have been too long scattered and separated on a basis of disease entities which are not truly separable. It will permit States to plan, in a coordinated fashion with adaptability and flexibility, proper programs for the whole range of the handicapped, rather than for only one or two groups. This, then, will result in a significantly more economical use of funds so that complete treatment and evaluation facilities for each of the disease categories will not have to be developed; rather joint usage will be required.

These community developmental disability centers will be manned by teams of physicians, such as pediatricians, neurologists, and psychiatrists; of social workers, nurses, rehabilitation specialists, and educators. How will these teams be made up? How will the members be trained? How will they be constantly upgraded in the care of patients? How will various team members properly understand their own role in relation to the other members of the team?

It is a well-known fact that there are three major steps in the training process: (1) recruitment through the creation of interest in a field, (2) the installation of theoretical information, (3) in-depth practice. The first step must be carried out with young students before a career choice is made. The only practical way that this can be done is through universities enlisting students on a part-time basis in combined academic and service activities. Theory during the training must be imparted by people of academic stature who can appeal to the intellect of the trainees. In-depth practice must be given with team approaches that serve as models for future operations.

It is, therefore, completely reasonable that this legislation have, as an essential component, Title II, entitled Amendments to Part B of the Mental Retardation Facilities Construction Act. If Title II is to be approved, there are two major questions which must be answered: why should university-affiliated facilities for the mentally retarded be training centers for personnel who will man the community developmental disability activities; and, why should the training that is to be given at the university-affiliated facilities be interdisciplinary in nature? I feel I can speak with some authority on these two issues. Johns Hopkins has had a university-affiliated facility in active operation since 1967 and I am presently Acting Director, in addition to my other duties as Chairman of the Department of Pediatrics. What we are doing is comparable to that of actual programs or anticipated programs in the eighteen other centers, even though there may be some very worthwhile differences. Therefore, I would like to speak from our own experience at The John F. Kennedy Institute for Habilitation of the Mentally and Physically Handicapped Child and use it as a model for other university-affiliated facilities.

From the standpoint of providing service to the handicapped, we have cared for about 400 children as inpatients and at least double that amount on an ambulatory basis. Each case is handled in the following way. Prior to admission, the child's reports are collected from the referring agencies. Physicians, psychologists, other hospitals, even school systems provide us with as much information as possible on the patient's particular kind of disability. If the Admission and Discharge Committee believes that the Kennedy Institute can be helpful to the patient and to his family, and, if the case is of value from the standpoint of training personnel, the case will be accepted. On admission, the child and his family are seen by representatives of the two major divisions—the biomedical and the behavioral—each equipped with adequate screening tools for the detection of defects pertinent to each of the particular disciplines of the Kennedy Institute. For example, information is obtained that is useful to ascertain the importance of social service, of psychology, of nursing, of occupational therapy, and of physical therapy to the particular patient so that a tentative diagnostic and treatment pathway can be obtained which is of optimal value to the patient and the family without marked duplication of services and unnecessary examination.

I have seen facilities where staff have not been developed in such an interdisciplinary manner and where every child is subjected to the same examination. In such a setting, I have seen a child receive an extensive speech and hearing examination, even though his mental age is only two or three months.

At the Kennedy Institute, the disciplines that can contribute to the particular case study the patient for a period of days. They then pool and compare their information in a major habilitation conference and the patient is assigned to a subsequent major discipline for therapeutic approaches which are monitored by other disciplines to ascertain the degree of improvement in relation to expectation. After a period of weeks, when specific therapeutic measures have been worked out, the family and representatives of community resources, such as community schools, social work programs, and day care facilities are brought in to learn the therapeutic approaches which can be applied specifically for that child in his home environment.

The Kennedy Institute has carried out a very substantial training program. Formal lectures and conferences are held regularly throughout each week rather than on a monthly or yearly schedule, as was the situation several years ago in the usual university environment. In the past year alone, we have trained over 175 nursing students, over 50 students in physical therapy, 5 psychiatrists, 4 psychologists, 17 special education teachers, 9 social work students, 30 medical students, 24 residents in pediatrics, 5 full-time pediatric fellows, and almost 75 students in speech and hearing. In addition, extensive course work has been given for clinical pathologists in genetic and biochemical detection; for graduate students in occupational therapy, rehabilitation, and for specialists in library sciences.

The numbers alone do not express the contributions which the university-affiliated facility has made from the training point of view. Each discipline has had intensive technical training in its own area; but, in addition, as an example, the physcal therapist has learned how his or her activities can complement the activities of the psychologist, the behavior modification specialist, the neurologist, and so on. In this way, gains made by one therapist are not eradicated by the efforts of another. For instance, a child who is undergoing conditioning procedures for improved socialization—so that the family can live peacefully while the child is in the home—presents a particular problem if the personnel carrying out physical therapy of that child do not follow similar principles of behavior modification and reward.

In the process of learning, the psychologist learns the role of the speech therapist in the treatment of the handicapped so that, if he becomes the primary referral source, as may be the case in the community, he can wisely choose the appropriate specialist. The pediatrician must learn the contributions of the educator. Likewise, if a retarded child is brought to a special educator, he must have an appreciation of the disciplines to be involved.

The Kennedy Institute's impact on student attitude at present is in contrast to the experience of an instructor in public health after conducting field trips for medical students to an oversized residential facility for the retarded. I quote from his paper, "Part of the shock of students who visit this facility may be related to the experience of being confronted with so many problems at once. The physician is confident that he has certain specific measures to offer an individual patient in discomfort: when the student is faced with a large number in severe distress, he is extremely uncomfortable merely because of the numbers. When students are interested in such a facility, they go largely as spectators rather than as physicians." By comparison, over 25 percent of the students at Johns Hopkins, in the course of their medical school experience, choose work in the Kennedy Institute in preference to other exciting experiences in the care of acutely-ill patients or patients with other diseases than those with chronic disability.

In the research area, major emphasis has been on the development of new treatment strategies, new medical rehabilitation approaches, and new forms of special education with careful comparisons of treatment benefits. For example, we are interested in studying, in a given patient, whether or not behavior modification will produce greater social benefit or greater educational benefit than more conventional approaches. One study of particular interest and importance to education is that of the talking typewriter. This is an instrument that costs approximately $40,000 with several thousand dollars annually for soft ware. A controlled experiment comparing this form of remedial reading for the handicapped with other forms has indicated the advantage, in the pilot program at least, of a human teacher over the machine—and at approximately one-fifth less cost. Other comparative treatment programs are underway which could have equally startling results.

The university-affiliated facilities have had an even more important role than simply these program objectives. Essentially, they have been unifiers of the university. They are a kind of mini-university: a meeting ground, a point of convergence for the medical sciences, the behavioral sciences, and the educational sciences. Unless these three areas concentrate their efforts in a coordinated manner, relatively little gain will be obtained by each carrying out his own independent efforts.

The university-affiliated facility is a meeting ground with a common concern for human beings in need of assistance. This need is strong motivation to effect cooperative and coordinated work. In this regard, the university-affiliated facilities have served as the major center of interest for the mentally and physically handicapped child in the academic community and in the general community along with the Kennedy Foundation and the National Association for Retarded Children, as government over the last four years has demonstrated a dwindling concern for the well-being of the retarded.

The university-affiliated facilities are also proving to be a focal point for educational approaches to difficult chronic problems in our society. They are also serving as proving grounds for the training of individuals in team practice.

Despite the serious financial limitations at the present time on medical institutions. The Johns Hopkins University as a private institution, though feeling very seriously the cutbacks in support by the present administration, is still giving considerable financial support to the Kennedy Institute. In one year alone, the Medical Institutions have contributed over one quarter of a million dollars in in-kind services and dollars to that facility.

More importantly even that this strengthening of internal university interest is the role that the university-affiliated facility is playing as a link to the community. It is essentially the bridge between the university academicians, and the community practitioners and families. It is a presentation of academics with relevance. First, it is a training resource for personnel from community programs, for public health nurses, and for black students in special education at Coppin State College who will provide the major special education resource to the City of Baltimore. It is a public information facility where activities for the retarded can be centralized, a meeting ground for parents' groups, and a center for State program planning. It is a training facility for the community with Neighborhood Youth Corps working on weekends and through the summer. It is the focus for a New Careers Program where poor people of Baltimore are given the opportunity to enter the health professions. These people are guided up a career ladder beginning as trainees to be a child life manager who is responsible for assisting the retarded in social skills. The next step for such workers is specialization in areas such as occupational therapy and physical therapy; or, working as psychology aides; or, in obtaining associate degrees through community colleges. Further educational progress may involve degree-granting colleges, and, eventually, professional schools.

It is a center for the training of day care workers and for pediatricians who come from practice to learn how they can better manage the retarded. It is a summer school for teachers who wish to learn more about the biomedical as well as educational aspects of the handicapped. And finally, it is a service facility for the community where children with severe educational problems may be brought to our school on a daily basis; where cerebral palsy clinics of charitable groups are conducted; and where the Cleft Palate Clinic of the Johns Hopkins Hospital meets as well as the child neurology clinics. In essence, it is a court of last resort for families seeking the most advanced medical, behavioral, and educational information for their child.

Our role, then, as we conceive it, is to develop new techniques of screening, new approaches to diagnosis, new methods of treatment, new ways to family education, new procedures in genetic counseling, new careers for personnel, and new disciplines to assist the retarded and handicapped. I believe the university-affiliated facilities are succeeding in this role.

The second question which I raised is why should training be interdisciplinary? What are the advantages of this seemingly expensive approach? Actually, the advantages are largely in the greater economy in the use of resources—

for the family, patient, and community. It is to assure that there is greater efficiency in assisting the child. Interdisciplinary means that one discipline must learn how to use, to a degree, the tools of another discipline, and work with that other discipline to develop some optimal path for the treatment of the child. We, in now way, mean to disparage the efforts of others in training, but if one analyzes the experiences which a trainee at the Kennedy Institute receives in psychology, for example, one can see that he learns the role of the neurologist of the psychiatrist, of the educator, and the abilities and limitations of the physical therapist. He develops a realistic appreciation of what can and cannot be accomplished. This is absolutely essential since so many of the handicapped reach treatment facilities by way of singular members of the scattered health team. For example, a teacher may be the major source of referral, or, perhaps, a public health nurse.

Let me illustrate some of the problems associated with this approach. An eighteen year old child, the daughter of an important family in this country, is being admitted to the Kennedy Institute this week. The child has a severe hearing disorder as well as some neurologic dysfunction. She was subjected to speech therapy for 8½ years despite the fact that the major deficiences are in the prevocational and intellectual areas. Not only was this a waste of financial and human resources, but valuable time has been lost that could have been put to far better use if more realistic expectations on the part of the people making the earlier referrals had been carried out.

What, then, should these centers be? They must be administered in a way that permits them to inter-relate as much as possible with the community Developmental Disability Facilities. They must be consultation centers for the satellite groups in the community which will carry out a large part of the service programs for the handicapped. They must be community training centers which train personnel for the satellite units and provide subsequent in-service training. They must be community research centers that can develop the essentials of better treatment and pass on this information to community programs for immediate application.

From a cost benefit standpoint, there is impressive evidence of what can be accomplished for the handicapped through these university-affiliated facilities. Yet, for those members of our society who are skeptical of the value of *any* efforts made for the handicapped, it is appropriate to point out what may be accomplished in terms of real benefit for the normal child.

Historically, medicine has learned a great deal of what is important for the normal from the study of disease. For example, the study of diabetes has contributed a great deal of information concerning normal carbohydrate metabolism. The study of cretinism, a bizarre form of retardation studied many years ago in Switzerland, demonstrated the role of the thyroid gland in normal people. The study of inborn errors of metabolism has provided information on the normal chemical pathways of the body. The study of Mongolism, or Down's Syndrome, I believe, will contribute very significantly to our understanding of the aging process.

Likewise, in the study of learning problems of the handicapped, much information can be obtained which will be valuable in understanding the normal child. For example, an appreciation of the existence of individual variation in learning abilities is absolutely critical to the most effective use of our educatonal resources. Individual variation is a concept which has not been fully appreciated by education and which comes from the study of individuals with disability. Conservative estimates of so-called normal school children with unusual profiles of intellectual capabilities vary from 15 to 25 per cent. Optimal education of these normal children requires individual teaching methods—the development of what might be called prescription teaching—to exploit the child's areas of strength and to attempt to bring his areas of weakness up to a normal level. It is essential that adequate scientific epidemiologic approaches in the description of learning disabilities be developed so that communities can plan and experiment with different types of resource allocations which ensure that our educational dollar buys a maximum education for all pupils over the spectrum of abilities ranging from the mentally handicapped to the child who is quite intelligent but has only specific learning disabilities.

Another example is in the area of psychiatry. The study of the basis for the strength of a family facing severe adversity can lead to improved ways of assisting the normal family to be prepared for hardship. Likewise, in the area of behavior modification, the use of conditioning procedures to remove unacceptable behavior has obvious application for normal child-rearing practices in determining the importance of rewards.

I should like to make sure that, within the legislative history of this bill, there is concern for the financial support of these centers. The construction funds should be allocated in a way that will permit optimal support of community resources. This will entail a careful programming to ensure that there is adequate geographical distribution of the university-affiliated facilities. Facilities must be built in locations and at university centers which will provide maximum support for regional or State community programs. In addition, the funds which are authorized for support are absolutely minimal and are a long way from being optimal.

I believe that the support of these facilities must be in four categories. First, sustained dollar support over a period of five to ten years for direct cost and administration. This would provide for core activities to ensure that there is continuity of staff from year to year which can lead to progressive improvement in programs. Second, there should be dollar support for specific programs which come from established agencies awarding funds in competition with other training, demonstration, and research activities. It is extremely important to assure that these centers are not excluded from such support programs because of the core support to which I referred. Third, support of indirect costs must be adequate to ensure universities and their affiliated facilities are not depleted of resources in the process of maintaining the high cost of the programs I have indicated. Fourth, there must be money for development so that emphasis can be placed on new methods of operation. I believe these funds should come from the efforts of the university-affiliated centers themselves through the recovery of monies for services performed, and should be used only for professional research and teaching just as universities use new funds to develop new programs. Such a mechanism will provide incentive for the acquisition of appropriate funds for services rendered.

These four support efforts must be for all elements of the center, not just the biomedical, or the educational, so that maximum balance can be obtained and maximum flexibility in the use of funds can be made possible. At the present time, there is a very serious imbalance which compromises the interdisciplinary approach. Either the biomedical support in some facilities is grossly underdeveloped and under-supported, or the educational support is seriously compromised, as is the situation in most of the facilities. Indeed, what has developed is competition instead of cooperation in acquiring funds for the major areas of the program, and this competition has seriously limited development. Methods must be found to reward joint activities so that divisions with educational responsibility and divisions with biomedical responsibility can be encouraged to work together. Likewise, centers with major emphasis on one or the other can also be encouraged to cooperate.

In conclusion then, I feel this legislation has great merit. It seems that the only way community programs, which are demanded by society, can be effectively implemented and improved on a year-to-year basis is through the parallel development of the university-affiliated facilities. As a way of illustrating the particular accomplishments in a somewhat graphic manner, I have asked some of the staff of the Kennedy Institute to accompany me to present very briefly, a few case examples of the kind of service programs upon which the framework of training and research are built. Accompanying me is Dr. Arnold Capute, who is Deputy Director of the Kennedy Institute, and he will present these cases. I appreciate the opportunity to appear before the Committee and I hope that the legislation will be successfully enacted.

Senator **KENNEDY**. The subcommittee will reconvene at 2 o'clock this afternoon.

(Whereupon, at 11:50 a.m. the subcommittee recessed, to reconvene at 2:00 p.m. the same day.)

AFTERNOON SESSION

Senator **KENNEDY**. The subcommittee will come to order. First of all I want to express my appreciation for the patience of the witnesses today. This is a busy day for all of us. I know this is a busy day for you, and so I particularly appreciate your understanding and patience.

Our next witness is Dr. Charles D. Barnett, from Columbia, S.C. I understand that South Carolina was the first State to set up a separate department of mental retardation, the department which Dr. Barnett now heads.

Prior to his present position, Dr. Barnett served as deputy commissioner of mental health and mental retardation in Texas. He has had extensive experience with State problems in the area of planning and coordinating comprehensive programs for the retarded, and we look forward to his testimony.

STATEMENT OF CHARLES D. BARNETT, PH. D., COMMISSIONER, SOUTH CAROLINA DEPARTMENT OF MENTAL RETARDATION, COLUMBIA, S.C., AND PRESIDENT, NATIONAL ASSOCIATION OF COORDINATORS OF STATE PROGRAMS FOR THE MENTALLY RETARDED

Mr. BARNETT. Thank you, Senator.

It is my pleasure and privilege to represent here today the chairman of the South Carolina Mental Retardation Commission, Dr. James B. Berry, of Marion, S.C., and our personable and dynamic Governor, Hon. Robert E. McNair, in basic support of S. 2846. The Developmental Disabilities Services and Facilities Construction Act of 1969.

Additionally, and in the capacity of president, I have the honor of representing the National Association of Coordinators of State Programs for the Mentally Retarded. Our association consists of a single individual from each of the several States representing the State agency heretofore appointed by the Governor to generally coordinate mental retardation planning within the State. Our association's purpose is to forward mental retardation services in the several States by promoting mutual assistance, cooperation, and the exchange of information and ideas in the administration of public mental retardation programs.

"Public mental retardation programs" as used here is meant to encompass the total programs dealing with institutional (residential) and community care in order to meet the needs of the mentally retarded and their families insofar as these programs are the responsibility of the individual States. The executive committee of our association unanimously endorses in principle and philosophy the content of S. 2846.

My purpose here today will be to comment briefly on S. 2846 and in so doing, I will put aside the inclination to share with you in any great detail the enormous needs which have accrued relative to mental retardation services in the various States. I will also set aside the perhaps even stronger inclination to verbalize the great bewilderment and concern that many of us in the States have felt for the past year or two regarding what is actually happening in Washington relative to the coordination and funding of mental retardation services and programs. Suffice it to say that we have often wondered who was doing what to whom and why? I must add that our confusion was often shared by Washington leaders themselves. Yet, despite this and despite sometimes outmoded communications and decision-making processes which have often excluded consumers and firing line administrators from seeing and reacting to legislation and regulations prior to their implementation, our programs have generally gone forward.

We see S. 2846 as offering the potential mechanism for recapturing the strong momentum which existed relative to mental retardation in the early and mid-1960's. The great tragedy of mental retardation today is that we know how to prevent many cases which are not being prevented and we know how to effectively serve those retarded and their families now with us who, too frequently due to a lack of resources, are not being served. Stated another way, the gap between what we are doing and what we know how to do for the retarded is ever increasing.

Permit me to cite two family situations which illustrate the magnitude of our challenge. Our department is currently holding a series of area hearings throughout South Carolina where, incidentally, some surveys show mental retardation to run as high as 10 to 12 percent in certain school-aged samples. At a recent hearing in Florence, we heard about two severely retarded, nonambulatory male youngsters living in a housetrailer with a pregnant mother, a possibly normal 4-year-old sibling and a father whose salary was grossly inadequate to provide the basic needs of the family. Our residential waiting list of almost 1,000 prevents our moving as rapidly as we would wish to be of assistance to such a family.

At the same hearing, we heard the father of a 22-year-old retarded son living at home plead for services to enable him to help his son there. In pointing to the son's waning potential and his own frustration at the lack of training and care services and facilities, the father noted that the highlight of this boy's day was a walk with his dog around town. And then, one of unplanned and unforgettable occurrences took place when the next speaker arose and addressing our commission stated:

> I, too, am the father of a retarded son, age six. Is this what I have to look forward to when he is 22—a walk around the town with his dog?

He sat down and a million more words could not have better made his point. The silence of the audience conveyed its receipt of the message.

History tells us it took 250 years to go from the short bow to the long bow and arrow. It took 10 years to go from piston aircraft to moon landings. Those of us sharing the responsibility, often wonder how long it will take to provide services for a youngster of six with special needs.

These two situations, then, the trailer family and the fathers of the two sons, illustrate the scope of the job before us still: To provide improved and available residential services to those who absolutely must have them; and to provide options or alternatives to residential placement through the expansion and/or development of a full range of community services for those who can be cared for at the local level and within the context of home and family.

Let me now move to some specific comments about S. 2846. First, some plaudits. We in South Carolina, with great need and limited resources, are not different from many other States. We have already realized that the needless duplication of services for every possible type of disability is an extremely expensive and cumbersome process.

Part of the answer to this then is coordination. Beyond this, the cost in frustration to consumers who must travel the confused service delivery pathways and the cost in time to those desperately in need of services is great. We have recently completed a study of services to the handicapped in the State and the manner in which S. 2846 provides a beginning focal point of coordination and support for the needed services, as was suggested by our study, is rather remarkable.

We welcome the opportunity to receive a formula award based on a comprehensive State plan and to share the responsibility among appropriate and designated State agencies for the administration and implementation of this plan. We commend the provision for a National Advisory Council and endorse the involvement of consumers in this effort. It is further our hope that one or more State coordinators will be chosen either as Council members or designated to serve in a technical capacity to the Council. The apparent flexibility of this entire proposal sounds refreshing and we urge it be maintained on that basis.

The extension of the university-affiliated construction program is welcomed with equal enthusiasm. Properly conducted, these programs can become both focal points for services and the training of a wide range of professional and technical personnel. It is significant that a new source of operating assistance be given to UAF programs as provided under section 203 of S. 2846.

The general approach to State matching based on a pooling of State-local contributions is a breakthrough. We urge that the regulations reflect the awareness that local contributions in manpower time and in volunteered space or services often have just as significant dollar values as cash.

Next, a few brief concerns and/or considerations. Hospital improvement projects (HIP) and hospital inservice training grants (HIST) have pumped new life into residential programs in recent years. We urge your consideration of the inclusion of these moneys also in the formula awards to States. We at the State level also urge that (1) the restriction on the age and size of the institution making it eligbile for support and (2) the general restriction of the use of the moneys to only the inresident population be modified to give States maximum flexibility in program development. These apparently were policy decisions in the past, not written in the law. Permitting a State to draw up a total plan will resolve this difficulty of times past.

We at the State level urge that full consideration be given to regulations and standards which are simple, logical, and meaningful. This is especially pertinent in the area of construction, where some States have found that excessive emphasis on hospitallike construction in nonmedical units entails added State cost not justifying the pursuit of Federal assistance in many cases.

We further urge that the National Association of Coordinators of State Programs for the Mentally Retarded be asked to review and comment on the proposed standards and regulations before they go into effect. Other groups such as the American Association on Mental Deficiency, the National Association for Retarded Children, and United Cerebral Palsy, to mention only a few, should also be asked to evaluate the proposed standards and regulations.

What will be the relationship, if any, of the President's Committee on Mental Retardation to the proposed National Advisory Council on Services and Facilities for the Developmentally Disabled? We feel that the presence of a national group directly appended to the President's Office gives mental retardation stature and visibility. Both the staff and membership of PCMR have done an outstanding job over the past several years. Perhaps PCMR and the new group could be combined into a President's Council on Services and Facilities for the Developmentally Disabled.

It is hard to imagine that the 12 members proposed for the National Advisory Council on Services and Facilities for the Developmentally Disabled will be a sufficient number. I am thinking in terms of the President's Committee on Mental Retardation where we have something in the neighborhood of 24 or 26 people. If indeed the new legislation is to cover a number of disabilities and to have specific requirements insofar as consumer involvement, then 12 members would not be sufficient.

In the development of university-affiliated programs, it is urged that some system be developed to give priority to applications from regions not already having such programs. Also, to insure that these programs are coordinated with other State service and training needs, it is suggested that the regulations reflect the need for State advisory council endorsement of the initial application and all other grant applications made under the present legislation which would affect or go to university-affiliated programs.

I want to say, Mr. Chairman, that I know we were all much impressed by the very fine display and presentation here this morning, as I know you were. Yet, I have to say quite honestly that in my travels and observation of some of these programs, many give me pause for reflection as to whether or not we are serving the mainstream of retardation and whether or not some of these programs are becoming terribly academic. I think we need to make every effort in an era of great need and limited resources to utilize these resources for all the retarded and not just a chosen few who happen to relate to some professional's research interests. I do not say this critically, but simply as a matter of observation and caution.

Senator **Kennedy**. Do you suggest that there ought to be more accurate evaluation of these programs? Do you think that would be helpful?

Mr. **Barnett**. This is what I am saying indirectly. I also believe that the involvement of these programs as a part of the State plan called for under S. 2846 will tend to enhance the awareness of our university-affiliated programs relative to service needs in States, and at the same time, will help leaders in the service areas become more aware of what the university-affiliated programs can do for them in terms of training, research, and services.

We urge that greatly simplified paperwork requirements be instituted where possible in all State-Federal dealings. Current application forms scare off small communities where services are often most desperately needed. Review delays often mean escalating costs in a number of areas. The State plan approach should assist in alleviating some of these current problems.

The emhpasis on poverty in urban or rural areas should not be tied down in the regulations to the extent of strangling a State. For example, current mental retardation staffing grants are often unrealistically tied to the model cities program. In many States, such a relationship is meaningless—especially if the local unit does not have matching funds or if the geographical region is not the most promising or needy. The State can best evaluate the needs and potentials of given areas, and we see this legislation as giving the State this opportunity.

I understand that we actually do not have an administration bill although we have had talk and comments about the stand of the administration relative to S. 2846. In the absence of having seen anything official on this and not having been here yesterday to hear the account of what was said, I still would like to comment about one point which someone mentioned this morning and which I assume correctly reflects the administration viewpoint.

The statement was made that in the so-called administration approach, States would have an opportunity to review and comment on applications. We must have more responsibility and authority than that. Otherwise our relationship with local units will be completely meaningless. I can recall in Texas where we had such a perogative under the MR Staffing Legislation. I can also remember rather vividly where we recommended, without mincing words, that a local application be turned down. I can recall equally vividly that the application was funded over our recommendation. The next year, with the decreasing Federal participation, this same applicant was at our doorstep asking for the State to pick up these funds. In other words, the action of our Federal friends served to more or less make a commitment for the State. Then local groups became agitated when we did not have the funds to assume the decreasing Federal portion. We need a better tie to local projects and applications than what I understand the administration proposal would offer.

Senator **Kennedy**. You would be more sympathetic to the approach in this legislation—S. 2846—which gives formula grants to the States then?

Dr. **Barnett**. Yes, sir, that is exactly what I am saying. I was trying to cite one particular example. It seems to me that the administration's suggestion is unrealistic and that it represents a failure to look back at what our experience has been. I certainly feel that the approach that the legislation here takes would give every opportunity to the State to get around this problem.

Realistic evaluation should also be made relative to maintenance of effort concerns by the Federal Government. Many local programs operate at a given level on a tenuous basis through funds derived from often unstable sources. Yet, at first glance, it appears we have a certain permanent level of operation ongoing in a given program. It is suggested that flexibility be given the State in differentiating between a stabilization of effort and a decrease in maintenance of effort. While we commend the concern expressed by such actions, the sound programs we seek for the future will not be based on the cookie sales of the past.

In summary, we feel that proposed legislation offers promising potential for assisting States to better coordination and to expand ongoing programs to the retarded and others with related developmental disabilities.

It is important that States be given the clear implication through all possible means that mental retardation is the primary condition with which this bill and this legislation deals. It is equally important that States designate key agencies familiar with the mental retardation problem to coordinate the provisions of this act. The legislation leaves this up to the State. We think this is fine, but we do want to point this out. Socially, economically and programatically, mental retardation is too big a problem and too significant a problem to let it drift back into the anonymity where it resided previously for so many years.

I would also emphasize that simply pooling the various funds currently available will not give us sufficient financial support. New moneys will be required to implement this legislation.

Senator **Kennedy**. Can you give us any idea as to the magnitude of the funding that is needed, Dr. Barnett? What should be the authorization level for this legislation? You have had a considerable amount of experience in different States. How much must we spend to meet the need?

Dr. **Barnett**. Senator, I am not prepared to suggest an amount in specific—this will require careful study. Let me use this analogy, however. Going back to my understanding of the so-called administration approach—funding at a level not less than the construction level for this year would mean only about $8 million for this act totally. Talking with one of the gentlemen here who represents mental health, I think the comparable figure for mental health this year would be something close to $100 million including certain moneys carried forward, staffing and construction.

We don't seek to gain funds for mental retardation and related disabilities at the expense of mental health or anyone else. But looking at the States I am familiar with, I know of no State where this kind of distribution of funds exists. Now, if the administration or whoever is involved here has some information we don't have, we would like to have it. It might help us to understand this position better.

Senator **Kennedy**. Why is there any disparity between mental retardation and mental health?

Dr. **Barnett**. I think it is clear that some people were here who did their "homework" better than the mental retardation people did back down the line. They were here and they were rightly seeking funds for their programs. Of course we were here too, but I don't think we were able to perhaps attract the same level of support or attention.

As I say, I don't think any of us here today would be critical of the mental health allocation. Not at all, because they need these funds. We simply need more money for mental retardation.

Senator **Kennedy**. I suppose there is a certain responsibility within HEW as well to remedy these kinds of inequities or at least to support the kinds of funding levels that are needed. I think all of us are aware of the budgetary restrictions. But when you are talking about the allocation of resources, I don't think any of us want to see mental retardation funds increased at the expense of mental health, cancer, heart, or stroke. Actually, from a personal point of view, I would like to see mental retardation funds increased by reducing our military expenditures.

So I don't think we are trying to get into a situation where we must play mental health off against mental retardation. But I am struck by the fact that when we talk about the level of funding included in this legislation, and the administration officials say we are unrealistic, we also see figures much larger for mental health. We know what the needs are in mental retardation and we realize that the level of funding in S. 2846 is not unrealistic in terms of the need.

Dr. BARNETT. I think you have said it very well. We could look at other examples. Under the provisions of S. 314(d), where 15 percent comes off the top of certain formula awards to States for mental health, it was a great mystery to us at the State level as to why mental retardation was not included in this. We simply feel that there is an inequity as far as the total breakout of money here.

Mr. Chairman, my State and the National Association of Coordinators of State Programs for the Mentally Retarded wish to express to you and your colleagues on the committee our heartfelt thanks for all you are doing and we ask you to continue your assistance and support for millions of individuals who, while they may never know a normal situation as we know of it, can attain new levels of independence, happiness, and productivity.

I thank you very much for your courtesy and the opportunity to share with you these thoughts and observations.

I would like to make one final point. You alluded this morning, after the UAF training demonstration involving the various youngsters, that if the other members of the committee had been here we would have no problem. I will say for the State coordinator group and South Carolina: we will be glad to come back. Just let us know when.

Senator KENNEDY. Very good. That is very helpful testimony. Each Senator will exercise his own best judgment on the questions raised here, but I would hope that your organization, as well as representatives of other groups here, will communicate with your Senators and Congressmen around the country on these questions.

I think your organization could be extremely helpful in communicating and letting us know through your State representatives the kind of program we ought to have.

I would like to hear from the people on these programs. I find that has an impact. In the legislation which is introduced and which is cosponsored here, we have tried to take the best ideas and suggestions that have come to us. I am sure there are many other changes that can be and should be made in the bill. We hope to have those suggestions too.

Dr. Barnett, you have performed a very useful service, and I hope that you will let us hear from you, and that you and the other members of your association will communicate your views to the rest of my colleagues. Thank you very much.

Dr. BARNETT. Thank you, Mr. Chairman.

Senator KENNEDY. Our next witness is Dr. John Noone.

Dr. Noone served with distinction as Superintendent of the District Training School for the mentally retarded in Laurel, Md., where he gained extensive experience with the problems of retarded children in the Washington metropolitan area. Dr. Noone has had the opportunity to work closely with parents as well as retarded children, and he has seen firsthand the need for more and better community programs. In addition, Dr. Noone has served as Chief of Mental Retardation at the National Institute of Mental Health, and he has taught at George Washington University and the University of Maryland.

I welcome you, Dr. Noone, and I appreciate your cooperation in rearranging your schedule.

STATEMENT OF JOHN J. NOONE, ED. D., EXECUTIVE DIRECTOR, AMERICAN ASSOCIATION ON MENTAL DEFICIENCY

Dr. NOONE. It is a pleasure, Senator Kennedy.

I am here this afternoon at the request of our president, Dr. Wesley White, who is recovering from a rather serious illness prior to going to the Commonwealth of Massachusetts, my native State, where he will be the first nonmedical superintendent of one of the State schools there.

He has asked me to convey to the members of the committee his regret that he could not be present. He asked that I provide this testimony for the committee.

The American Association on Mental Deficiency, numbering over 9,500 professionals working in all levels of mental retardation, welcomes this opportunity to testify on behalf of S. 2846, the Developmental Disabilities Services and Facilities Act of 1969.

We are wholeheartedly in favor of this bill, and completely support the concept of a mechanism which will allow the States to develop and implement a comprehensive and continuing plan to meet the current and future needs of those affected by developmental disabilities.

We are pleased to note the provisions for the construction of facilities for these services, and the amendments for the expansion of the university-affiliated mental retardation facilities.

We seek here the operational support of these services.

When Congress passed the first major legislation for the mentally retarded in 1963, it gave new hope for the mentally retarded, their families, and those who work with them daily.

The provisions for construction of community facilities, centers for research, and university-affiliated facilities, better staffing patterns, the hospital improvement program, and its complementary hospital in-service training program, and other service-oriented programs have been like an oasis in a desert.

For years professionals had been aware of their inability to cope with tremendous problems in working with the mentally retarded, many of whom have concomitant disabilities rendering their development inadequate.

A grateful community bestows its thanks upon you and your predecessors.

There are still needs to be met, and we believe the provisions of S. 2846 will carry us a long way toward attaining the goal of a much better life for those so handicapped.

We are impressed with several key features of this bill, especially the opportunity for a State to develop a comprehensive plan to assess its program needs, and the authorization of allotments to States based on population, need for services, and finances.

This formula grant program is much more equitable and expeditious, and it should eliminate many of the discrepancies of the previous protect grant programs. It will tend to place responsibility back on the States and the local communities to plan wisely.

However, I think consideration needs to be given for more appropriate time for the States to plan. We note section 139 of the bill suggests that March 1, 1970, be the time when the Secretary will provide standards for the States. I think that the States will need a little more time in which to prepare. I am sure the committee can make the proper adjustments.

On the National Advisory Council, I would agree with my colleague, Dr. Barnett, that the membership be expanded. I think 12 members are now called for. For a program such as this, we need a greatly expanded council.

I suggest also that the university community be represented on the National Advisory Council; and by the same token, when the States establish their advisory councils, that the academic and the college community be represented on this important group.

We are pleased to note the provision for nonprofit agencies, institutions, and organizations to participate in the program by membership on the State council, providing services, and being eligible to receive funds for programs within the purview of the overall State plan. Too often we have not looked to the private sector to serve as a copartner in helping the handicapped and their families.

When I went back to the office yesterday afternoon, going through my mail, I came across correspondence from California. Two ladies here are very interested in opening a facility for the mentally retarded. They indicated they had gone through five major steps, received permission from all the respective agencies in the State, but then they say, "Now we have come to a standstill. Because of the tight money, high interest situation, we have been unable to obtain a loan."

I think this brings out the need for the private group to be more involved with the State programs, so that they can have "a piece of the action."

The Developmental Disabilities Services Act will enable States to look closely at local services and perhaps make a fresh beginning at the outset of the problem.

We all know that the sooner the disabling condition is diagnosed and services rendered, the better opportunity the child has for a more normal life, and the less trauma befalls the family. With more adequate services in the community, there is less likelihood that the child will have to leave home for residential or long-term care in a distant facility.

Diagnostic evaluation, day care, recreational and counseling services for the child and parents, preschool programs, vocational rehabilitation and training, are but a few of the services needed on the local—urban, and rural—level to help the developmentally disabled.

The American Association on Mental Deficiency recognizes the lack of standards in many of these areas for the mentally retarded, and is about to embark on a project to develop guidelines and standards. These should be of some value to all handicaps enumerated in this bill, as States formulate plans to develop programs of service on the community level.

In this context, too, section 139(2) indicates that there will need to be standards developed for the States.

From experience, our association can point to a rather long and difficult role to develop and pull together adequate standards for facilities. We have had quite a bit of experience on this with our residential programs.

We recognize the great need for standards on day care and community programs.

Residential programs for the mentally retarded continue to concern and worry us. Excellent progress has been made in some States due to the intervention of the hospital improvement program and the hospital in-service training program under progressive leadership.

However, the President's Committee on Mental Retardation in its report, MR 68—The Edge of Change, points to the deplorable conditions: many of the 200,000 residents live where the average age of the buildings is 44 years, and the average daily cost for care is $7.60, with some amounts down to just over $3 per day. Overcrowding, distance from urban centers, poor salary scales for attendants, and insufficiently trained staff are a few of the reasons for the plight of these institutions.

Our association recently studied 134 of 168 public institutions in the country, and found 185,000 residents in these facilities. Thirty-two institutions house from 2,000 to over 3,000 persons and accommodate 94,940 individuals. I think this comes out to something like 2,900 individuals per residential facility.

We drop down to a mid-category of population, 500 to a thousand in 74 of these "average size" installations, where there were 82,400 people living. This comes out to about 1,100 people per institution.

In this study we found that none of the essential standards in the care of residents and only one essential standard in the socio-education section were met by 75 percent of the institutions evaluated.

The literature is rife with examples of dehumanizing conditions in our institutions, and the time has come for us to do something.

It is our hope that S. 2846 will be available to help not only the public facilities, but also the many smaller, private, nonprofit residential centers and homes. Our association has recently granted status to these private residential facilities, and we plan definitive programs to help them attain standards of care for the retarded so they can bring the full force of their particular skills and knowledge to the field. They are a positive influence that must be expanded and utilized.

Manpower is crucial for the development and execution of programs of service. We are grateful for the many provisions for training professionals offered by our colleges and universities in recent years.

I think the examples that we saw this morning, showing the multidisciplinary teams in action, are vivid examples of what can be done with a well-trained staff.

The amendments to Part B of the Mental Retardation Facilities Construction Act indicate an emphasis on interdisciplinary training, and this should prepare the student to participate more meaningfully with his colleagues in the other disciplines as a member of the team.

Too often, many of us see the students in their separate islands, in the universities working by themselves, and with little opportunity to begin to communicate with their follow students in other disciplines. Small wonder, then, when they graduate and come out in the professional world, they do not, in too many cases, know how to talk definitively with their professional colleagues. We think this is a good feature of the bill.

Those with developmental disabilities require a great deal of expertise and knowledge to diagnose, serve, and train. No one profession has a corner on the market. Professionals and para-professionals must all work together.

Title II, section 122(b), authorizes a more equitable increase in appropriations from $7 million in fiscal year 1971 up to $20 million for the period ending fiscal year 1975. This should give stability to the programs and insure continuity of training. There is noted in recent years a marked decrease in the appropriations compared to what had originally been authorized.

The provision for "administering and operating demonstration facilities and interdisciplinary training programs for personnel," secton 122(a), is a welcome and important facet of this bill.

We still struggle with shortages in manpower training and recruitment. Hopefully we can make possible an invitation for more students to be attracted to the medical, dental, behavioral, social, and educational sciences.

The American Association on Metal Deficiency is pleased to support this bill, and looks forward to its passage by the Congress. We believe it will put the total program for the developmentally disabled on a sound foundation and enable the States to formulate both short-range and long-range plans.

The greatest benefits will accrue to the handicapped, enabling them to lead fuller lives, to their parents and families, and to the many professionals and para-professional workers in their respective areas of concern.

Thank you very much, Senator, for this opportunity to come before this committee.

Senator KENNEDY. Thank you very much, Dr. Noone.

You made a comment that the States have been extremely slow in developing standards. Could you elaborate on what is being done? Which States have done a good job? What needs to be done in other States?

Dr. NOONE. I think the States have developed parts of their overall planning, but I don't think that planning has involved the actual standards for facilities or programs.

Perhaps the analogy might be for the residential programs. We have institutions dating back to 1847, but not until 1964 did we have actual standards for the provision of care for the residents in the institution.

By the same token, I don't think we have standards in the States for the day care programs.

I think one of the gentlemen this morning indicated that a school would not take one of the children because the child was not dry. Apparently it is felt that children must be dry in order to attend school.

I can appreciate the role of the teacher who has to work with the particular disabilities, but also, with standards, with training, many of these children can use toilet facilities adequately, with proper standards, and then they can take full benefit of the educational opportunities in the classroom.

As far as the day care programs are concerned, what kind of standards do we have? How many children can go in, what age, what kind of staff—we just don't have them. It will take a tremendous amount of time.

Senator **Kennedy**. Dr. Noone, you can tell us about the progress in various States in planning their programs to take advantage of the present legislation.

Are you sufficiently convinced, from your study of what various States have done, that they will be able to develop a program to take advantage of the proposed legislation before us today?

Dr. **Noone**. I believe so, Senator.

The 50 States did have an opportunity to plan, through Federal funds which expired a year ago, so they do have at hand some plans. How adequate they are, I can not say, but I think the progressive States have made a big dent in recognizing their problems.

It would seem to me that under a mechanism as envisioned by S. 2846, this would give them added impetus to update and implement their planning.

I think by and large they will be able to do it. I would like to think that our Association and our colleague associations would be in a position to be of great value to the States in this whole effort.

Now, in terms of the standards that we mentioned, I think I was alluding earlier to the great amount of time that our Association devoted to the development of standards.

A monograph came out in 1964 on residential standards. This was followed by an evaluation of State institutions based on these standards. Now, the third leg of that triangle has been completed by the establishment of a Joint Commission on the Accreditation of Residential Facilities under VCAH, in Chicago.

But this took a long period of time, and we need similar standards for day programs.

We could go through the same steps to provide the States and the local communities with standards to assist them in the promulgation of adequate programs.

Senator **Kennedy**. What is your feeling about the balance between basic research and research that is being done in terms of training and education?

Dr. **Noone**. Quite frankly, not enough.

Senator **Kennedy**. Not enough training programs?

Dr. **Noone**. Yes. I think we have been enamored of the esoteric research which has gone on in PKU and in genetics.

I don't deny the great efforts that my professional colleagues have made in this field. Certainly it has been most helpful in terms of prevention. But I think this alludes to the small percentage of those who are severely and profoundly retarded.

If one looks at the great number of the moderately retarded and mildly retarded, we need to know more from research findings of how we can work with them.

Talking to an associate recently, he said, "You know, we have all kinds of information on how kids react in school, but we have very little on assessment of the teachers and those who are providing the service." Again, this is a bit of programmatic research that I think is quite necessary.

So in answer to your question, sir, I should say that we should begin to provide a bit more emphasis on the social, educational, and behavioral types of research.

Senator **Kennedy**. Thank you very much. I appreciate your appearance here.

Dr. **Noone**. It has been a pleasure. Thank you.

Senator **Kennedy**. Our final witness in these hearings will be Leonard Ganser, who is Administrator of the Division of Mental Hygiene, Department of Health and Social Services of the State of Wisconsin.

He is accompanied by Mr. Harry C. Schnibbe, Executive Director of the National Association of State and Mental Health Program Directors.

Dr. Ganser is a native of Wisconsin. He served in the Public Health Service during World War II. He has spent almost his entire career in service to the State institutions of Wisconsin, which is nationally recognized as having some of the most progressive mental retardation programs in the country.

Mr. Schnibbe is well known to us as a former administrative assistant to Senator John Carroll of Colorado.

Welcome to both of you.

STATEMENT OF LEONARD J. GANSER, M.D., ADMINISTRATOR, DIVISION OF MENTAL HYGIENE, DEPARTMENT OF HEALTH AND SOCIAL SERVICES, STATE OF WISCONSIN; ACCOMPANIED BY HARRY C. SCHNIBBE, EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF STATE MENTAL HEALTH PROGRAM DIRECTORS

Dr. **Ganser**. Thank you, Senator Kennedy.

I represent an association supported by State mental health and mental retardation agencies. We have administrative responsibility for the majority of the mental retardation programs in the country.

I think you are familiar with the purposes of this association, because members have testified before this committee frequently in the past.

I did want to clarify for you our relationship with the association which Dr. Barnett represents.

Dr. Barnett represents the Association of State Mental Retardation Coordinators. These are men who have been designated from a State agency as coordinators of mental retardation programs in a State. In the majority of the States these programs are in the mental health agency.

For instance, the Wisconsin representative in Dr. Barnett's association is a gentleman you know, Mr. Harvey Stevens. Mr. Stevens received the Kennedy Foundation Award for his work in mental retardation. He is the Director of the Bureau of Mental Retardation in my agency.

Our testimony here is in summary form. I would like not to read it, but to make reference to some points in it, so that there would be an opportunity for questions.

This, of course, is all in relationship to the proposed legislation that we are considering here.

The State mental health directors do support very strongly, and feel that we need, long-term Federal support of care and treatment programs, education and rehabilitation of the mentally retarded.

In our testimony we refer to State programs, but this includes support for local programs, especially involving the State agency as the coordinator of those programs.

In the present system of Federal matching, these programs are fragmented. They are difficult to deal with because of inflexibility. They have very specific purposes that may not fit in one State or another. They tend to be competitive, and they are ill planned.

So we are suggesting that these programs be junked in favor of something that is more manageable, something that can result in more effective care for the individuals who are retarded, and more help to their families.

In the Federal agency and in the States there are not well organized programs for the mentally retarded. In part this is because we have not had proper stimulation from the Federal agency that we have had in some other areas.

Items 5 and 6 in my prepared statement—item 5 is a list of Federal-State mental retardation services that you are all familiar with.

Item 6 is a listing of existing Federal programs that compete with each other at the State and local level. Again you are familiar with all of them.

We think that as many of these programs as possible should be consolidated into one program at the State level, so that the State can use these effectively in coordinating them and interdigitating them with the State's significant investment in care of the mentally retarded.

We also think it is a good idea to relate the functional problems originating in childhood that this legislation anticipates.

I think the examples that Dr. Cooke showed here this morning were excellent examples of the need to relate these disabilities.

I think these are examples that I or anyone else who has worked with the retarded would find very familiar. These are examples of youngsters that we have in many of our institutions. There is an unnatural distinction of these youngsters—mental retardation being the condition that qualifies or excludes them from some very necessary services. I think the developmental disabilities concept is one that makes it possible to be sure that even the relatively rare kind of disability gets the full-scale kind of service that a person has a right to expect.

We also, of course, are especially concerned about the continued care of the adult mentally retarded.

Educational programs, and vocational rehabilitation programs, frequently are related to the disabled who are of school age. They are related to people who have vocational potential.

There are many, many mentally retarded who are in neither one of these groups, and this is a group of mentally retarded who cause their parents a great deal of concern.

One of the most frequent requests that I get in the agency I operate is from parents who have a mentally retarded child who is not a vocational rehabilitation candidate, who is not of school age, and who can live with some degree of independence in the community. They are concerned about what is going to happen to him, when they die. This is a very serious problem for these people.

What we do need is the opportunity to develop a comprehensive program at the State level, and we think it would be most important to have a comprehensive program at the Federal level to provide for leadership in this effort.

This means that we would have to combine the programs that we have talked about here into one kind of consolidated grant, and as many of them as possible.

Obviously, some of them are not going to be combined into a single grant, because there are some very traditional separations, but all of those that are possible, we feel, should be put into one consolidated grant. We think it would be wise to cover all five categories of the developmentally disabled that have been described.

We think this should be a formula grant, that it should be one grant each year to each State. The purpose of it should be to provide on-going Federal assistance for construction, operation, maintenance, staffing, training, transportation, research, planning for residential, day care, out-patient, and the full range of services that are required.

The next item might be somewhat controversial, but we feel rather strongly that there needs to be permanent support. The State legislatures and the State agencies find it very difficult to develop sound programs when the Federal support is on a project basis. They find it very difficult to devlop sound, ongoing programs without stable support to look forward to over a period of time.

The question of how much that support should be in terms of percentages—there are a lot of different opinions about that, but it has to be a significant amount.

With this kind of consolidated grant, each State could then be required to have a comprehensive State plan.

We have planning projects, and we have developed some comprehensive plans, but again they were one-shot kinds of affairs.

I think the mechanism that is offered here would provide for consistent planning, for continued review of the State plan and a plan that would encompass recipients other than those involved in construction grants.

Each State should be given the right to determine within limits the allocations of the Federal grant according to its own priorities.

Giving the States the power to review and comment is less than nothing, as far as most of the granting programs are concerned. As a matter of fact, the power to review and comment, as the local community individual might see it, may even weaken their respect for the State agency that has the major responsibility for mental retardation.

In my State, for instance, the State expenditures in mental retardation are between $50 and $60 million a year. In order to be sure there is close and proper coordination between those expenditures and the dollars coming from Federal programs, it is clear that the State agency needs to have a considerable force in this kind of consolidated grant.

Senator **Kennedy**. Did you say that State expenditures for mental retardation in Wisconsin are $50 to $60 million?

Dr. **Ganser**. $50 to $60 million of money expended.

Senator **Kennedy**. On mental retardation?

Dr. **Ganser**. Yes.

Senator **Kennedy**. Then, you must probably go far beyond matching the total Federal funds available to the State for mental retardation programs.

Dr. **Ganser**. I think this is a case you will find in many States, because we have very expensive institutional operations.

Senator **Kennedy**. Will you give us your judgment on the level of funds recommended in this bill? Do you think they are excessive?

Dr. **Ganser**. I think the funds will have to be sufficient to have a significant impact. Perhaps I can indicate what I mean with another example from Wisconsin.

We now have a construction grant that has been approved which will take our allocation of Federal construction money for the next 3 years. One program. It is in Milwaukee. It is a relatively large program, even though the 3 years' allocation of money is not great in terms of construction of facilities. It does not provide for bedspace. It consists entirely of sheltered workshop programs.

Therefore, in the State of Wisconsin the construction aspects of the present law will have no additional impact for 3 full years. By that time, community programs that are now interested will have lost the impetus to apply for funds.

Another example: We have five staffing grants approved this year. All were funded at somewhere around the 50-percent level.

These are all local programs. None of the construction or staffing in our State goes into the State-operated programs—only local programs.

Those five operations had to curtail by 50 percent the programs they had in mind when they made the application.

I hope these examples illustrate that there has to be sufficient funding to have an impact, to have a noticeable effect on the speed with which community resources develop.

The $100 million figure in my prepared testimony is as good as I could come up with. I think that would have a significant impact. Whatever figure that is decided on must be in that area.

State investments in mental retardation programs are very large—a billion dollars or more each year in all of the 50 States. Because some of our program is tied up in expensive care for the most severely handicapped, we need this Federal money to provide the cutting edge to get community programs going.

I want to make one additional comment about the matter of the public agencies in terms of receiving these funds. I think this is important, but I also think it is especailly important for the private nonprofit agencies to receive these funds.

Again, if I can use Wisconsin as an example, we have a day care MR program which the State funds 40 percent. Since 1963, when that legislation took effect, we have developed 85 day care MR resources in the communities that now use almost $4 million of State money, even at this 40 percent. A good share of the 60 percent of local money is private nonprofit money, especially coming from parent groups and so on.

They have done a tremendous job of extending these services so that at this point we serve between 3,000 and 4,000 people in day programs. Many of these would be in institutions under other circumstances.

Senator **Kennedy**. I ought to know, but how many day care centers do we have in Massachusetts? Do you know, by any chance?

Dr. **Ganser**. It seems to me I heard Dr. Greenblatt say last week something like 30.

I believe they are developing now. The States should be required to provide matching funds. Eligibility of programs: We feel that while it is good to have Federal money go into new programs, there are many inadequate old programs. There are many old programs that need beefing up. We have examples, of course, right now.

The hospital improvement projects and the hospital inservice training projects are efforts to beef up old programs. I think around the country there has been great success in providing additional resources in the existing institutions for the mentally retarded.

Regarding the intended Federal Council membership: We tend to agree with the previous testimony. We would feel that the relationship between this Federal Council and the President's Committee would certainly have to be clarified.

In summary, we would urge you to institute a Federal matching grant system to serve the developmentally disabled.

We feel that the money in this grant system should be enough to have a significant impact.

The program should have at least $100 million for the first year.

One hundred million dollars is an amount equivalent to what we would consider to be proper funding of the existing mental retardation facilities construction and staffing programs, and the MR hospital improvement and inservice training grants.

The Federal Government should place in the hands of the State full power to determine the allocation of the Federal grant after priorities are established and after a comprehensive State plan is developed for services for the developmentally disabled. This State plan will be reviewed by the Federal agency and by the Federal Council.

In my opinion, as an executive of a State agency, it is difficult enough to administer a program at a State level covering a State. Wisconsin is not one of the largest States. We have about four and a half million population, and a moderate amount of land, but even at that is it difficult to administer a program covering a State of our size.

I believe that it is impossible to effectively administer a program from the Federal agency level that is meant to get down to the care of individuals in a local community.

We have day-care programs that in small rural communities serve 10 people. This kind of resource cannot deal effectively with the Federal Government.

This program should have no time limit. It should be a program of permanent Federal matching support, so that we can establish permanent programs and plan for the future.

It should be built on formula grants. The project grant idea does not appear to us to be equitable.

Efforts must be made to get these kinds of program resources to the deprived areas, whether they be rural or urban. It is clear that these areas have the least resources to develop project applications.

We endorse the concepts of the partnership in health, getting various grants to the developmentally disabled in one formula grant, and returning the responsibility where it belongs, to the State government.

We think most of these considerations are included in S. 2846. We therefore think that this would be an excellent medium to get most of these considerations into operation.

I will not comment on the university affiliated facilities, because there already has been very eloquent testimony on this matter, except to say that we need to work very hard to have the capacity to extend the results from these facilities out into the operational area.

Again, being an administrator, I think I can say that one of our greatest handicaps is not being able to implement the things we already know. We are way ahead of what it is possible to implement.

I can say that very easily, because I am to blame, and most agency administrators realize that with better administrative structure, with better resources, they can do a much better job of getting services down to the level of the individual who needs care, which is where the services belong.

I shall be very glad to answer any questions you may have, Senator.

Senator **Kennedy**. Mr. Schnibbe, would you like to make a comment?

Mr. **Schnibbe**. Not at this time, thank you, Senator.

Senator **Kennedy**. Dr. Ganser, I would like to ask whether there should be a continuing obligation for the Federal Government to support ongoing programs for the retarded?

What I am thinking of is, should the Federal Government give permanent support to these various centers and facilities?

Dr. **Ganser**. I think the Federal Government already supports services to the mentally retarded on a continuing or permanent basis in several different ways, through educational funds, through welfare funds, through aid to the disabled, medical assistance funds, and so on, so I think the Federal Government is already providing ongoing, continuous support to the mentally retarded in several ways.

Now, these Federal funds assure the mentally retarded person of his right for these services, and are extremely important, but there is no ongoing Federal support for some of the unique and unusual programs that mentally retarded need outside of these areas. I think there should be ongoing or permanent Federal support for those programs, too.

Senator **Kennedy**. If we are just leaving the States to develop their programs themselves, how can we really be assured that high quality programs will be developed in all States?

Dr. **Ganser**. The quality of programs in States right now is very spotty. I think that any Federal program would have to take States from where they are now, but I believe that through expectations of planning and improvement, the Federal Government and the Congress could be assured that the money was being used appropriately.

I think that it is important to strengthen the State agency, rather than to complain about the inadequacy of the State agency. We all have inadequacy. We fell very strongly that the best way for the Federal Government to be sure the State agency is doing a good job is to insist that they provide adequate plans, to provide them with resources to strengthen the State agency to get the people who are competent to carry out those plans.

I don't think this approach would be difficult to monitor. I think it can be monitored from the plan and the planned implementation point of view.

Senator **Kennedy**. I understand that the record of the various State agencies that have reviewed and commented on grants in the mental health and mental retardation field is somewhat uneven. Do you have any comment on that?

Dr. **Ganser**. I don't think I am very well able to comment on other States, but I would guess you are correct. It is spotty, because of the equivocal nature of the States authorization, especially in the staffing grants.

There is a marked difference from the construction grants, where the State agency has a clear responsibility to approve before a grant is processed by the Federal agency.

In the staffing grants, the authority and responsibility of the State agency is equivocal and as a result they have very different methods of handling this, and in some cases, as a result of the kind of experience Dr. Barnett mentioned here, they see little point to spending a lot of time in reviewing them.

Senator **Kennedy**. We have talked about where the most serious problems of mental retardation exist, whether they exist in the urban areas and the poverty areas, or in some other areas. You were here this morning when we had splendid testimony that enlightened us on this matter. On the basis of your experience in one of the most effective State programs, can you tell us where the need is greatest?

Dr. **Ganser**. I would agree with what I think was said earlier, and that its that the problem of what might be called the basic mentally retarded, with some organic components to it, is fairly standard throughout almost any community and any cost level.

The sociocultural kind of mental retardation is most likely to be present in those communities, those families, those areas of living where there is little stimulation of he youngster.

Again, I think one sees a great deal of this in compacted city areas, but in Wisconsin we also see a great deal of it in rural areas, where we have rural poor, rural uneducated, who are unable to stimulate their families properly, and we have many experiences with this kind of youngster coming into a hospital, being there a couple of months, being fully evaluated, and going out into a family care home, and within a relatively short period of time showing an increase in IQ and indicating basically a normal intelligence, if we get them early enough.

We would feel that in our State the department of public instruction is providing the major kind of resource for these socioculturally deprived youngsters, because they tend to me mildly retarded, and they tend to be able to make use of that kind of service, the special class kind of service.

The severely retarded, of course, are the ones that are apt to be left without any help.

Senator **Kennedy**. I want to thank you very much. It is very helpful to have your comments.

I express again my appreciation for your patience with us here.

Mr. **Schnibbe**. I appreciate your presence here as well.

(The prepared statement of Dr. Ganser follows:)

PREPARED STATEMENT OF LEONARD GANSER, M.D., REPRESENTING NATIONAL ASSOCIATION OF STATE MENTAL HEALTH PROGRAM DIRECTORS

Accompanied by: Harry C. Schnibbe, Executive Director, National Association of State Mental Health Program Directors, Washington, D.C.

Representing:

Directors of the 54 state and territorial mental health programs.

In every U.S. jurisdiction except one (Colorado) the director of the state mental health agency administers programs for care and treatment which include mentally retarded persons.

164,641 mentally retarded persons annually are cared for in 147 mental hospitals and other residential treatment facilities administered by the state mental health agencies. In addition, our members administer or partially fund hundreds of day care, training and diagnostic programs in local communities.

In 31 states and territories the state mental health director is exclusively responsible for administration of the residential programs for mentally retarded children and adults who are under state care. (In 21 other states responsibility is shared with another state authority, with the mental health agency, in some instances, acquiring full responsibility for the *adult* retarded.)

* * * * * * *

POSITION ON ISSUE BEFORE THE U.S. SENATE

1. The state mental health directors support the concept of long-term federal support of state care, treatment, education and rehabilitation of the mentally retarded.

2. However—the present system of federal matching support of state and local MR programs is—

fragmented;
inflexible;
competitive;
ill-planned; and
un-realistic.

3. We therefore recommend that it be junked in favor of a sensible new system.

4. The present "system" of care for the mentally retarded is not a "system" at all—at either the *federal* level or the *state-local* level.

It is a mish-mash of competing schemes, dollars and services.

5. Here are some of the federal-state MR services fighting each other for federal attention and a relatively insignificant number of federal dollars:

(1) residential facilities (*construction*)
(2) residential facilities (*operating*)
(3) non-residential facilities (*construction*)
(4) non-residential facilities (*operating*)
(5) training and/or education of the mentally handicapped
(6) education of teachers and care personnel serving the mentally handicapped
(7) rehabilitation programs
(8) categorical aid welfare programs
(9) medical care programs
(10) protective payment programs
(11) planning
(12) diagnostic services
(13) research
(14) demonstration projects

6. Here are some of the existing federal programs that compete with each other at the state and local level for priority position to grab the presently meager sum of federal grant dollars:

(1) MR hospital improvement program
(2) MR hospital in-service-training
(3) MR community facilities construction
(4) MR community facilities staffing, operation and maintenance
(5) University-affiliated demonstration programs; construction and operation
(6) Research centers on mental disability
(7) Education of teachers of the mentally disabled
(8) Training of the mentally disabled

7. As many of these programs as possible should be consolidated at the state level.

8. *Furthermore . . . .* persons with related functional problems originating in childhood should have equal access to the established federal-state-local programs:

(1) mental retardation
(2) cerebral palsy
(3) epilepsy
(4) congenital malformations
(5) sensory disorders

9. These programs should be available not only to developmentally disabled children, but also (often neglected) adults.

10. We need at both state and federal levels a *comprehensive program* for care, treatment, education and rehabilitation of the developmentally disabled.

This means the Congress this year, instead of the usual jerry-built, patch-work-quilt of scattered services, should give the states *ONE*, consolidated grant. It should be a substantial sum of money and it should have these features:

Coverage: All five categories of developmentally disabled described above.

Type: "FORMULA" grant; one grant each year to each state.

Purpose: To provide federal assistance, for construction, operation, maintenance, staffing, training, transportation, research, planning, etc., of residential, day care, outpatient and other programs for the developmentally disabled.

Duration: permanent.

Planning and Regulation: each state should be required to have a *comprehensive state plan*, providing for a wide range of services; federal government should have *one* overall advisory council to review and oversee the general effectiveness of the program (this would provide some control over existing federal review councils that really have little expertise in the problems of the developmentally disabled).

State right: each state must be given the right to determine the allocation of the federal grant according to its own *PRIORITIES*. Giving the states simply the power to "review and comment" is less than nothing. I can say here and now the states will reject such a system as already proven to be ineffective.

Recipients: some of the grant money *must* pass through to local level; recipients could be state or local public agencies, and private non-profit agencies—those agencies with the most effective and diversified capabilities.

Matching condition: state would be required to participate with federal government in funding the operation, staffing, maintenance of approved programs.

Eligibility: state should be allowed to use the federal money not only for new or planned programs, but also for established *old* programs and facilities.

Federal Council Membership: the federal council should have at least four members representing *state* mental retardation programs; also at least four members representing *consumers* of service.

11. *Summary:*

The state directors of mental health programs urge the Congress to institute a federal matching grant system to serve the developmentally disabled.

The money in this grant system should be *AT LEAST* $100 million for the first year (which will be equivalent to *proper* funding of existing construction, staffing, research and training programs now administered by the Division of Mental Retardation in S.R.S.).

The federal government (*in the spirit of PL 90–577 . . . . . the Intergovernmental Cooperation Act of 1968*) should place in the hands of the states full power to determine the allocation of the federal grant, after *priorities* are established in a "COMPREHENSIVE STATE PLAN FOR SERVICES FOR THE DEVELOPMENTALLY DISABLED". (The state plans would be reviewed by a newly established Federal Council.)

The program should have no time-limit on it. It should be a program of permanent federal matching support.

The program should be built on "*formula grants*" to the states. The so-called "project grants" have been discredited as inequitable.

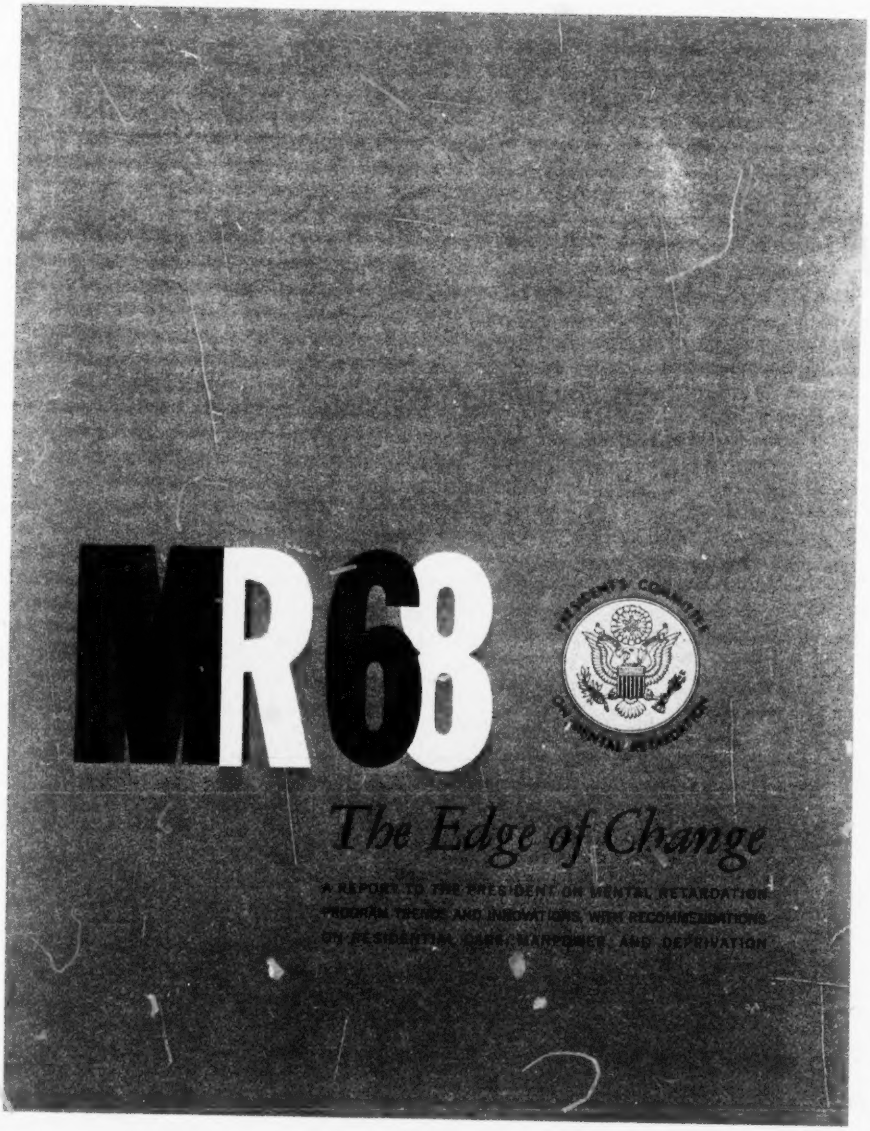
As in the "Partnership for Health" (PL 89–749) program, it is time to consolidate the various grants to the developmentally disabled into one "formula" grant and return responsibility for planning, priority setting and allocation to where it belongs—the State governments.

Senator KENNEDY. This concludes our hearings. Extremely valuable testimony and information has been received during the course of the hearings, and I think all of us benefited from the comments that have been made.

I hope that we can put some of these comments to work in improving the bill, and I know that we will probably call on all of you again in the coming months.

I want to thank each of you for your attendance here.

At the conclusion of the hearings, I ask that the following documents be printed in the record: (1) MR 68, the second report of the President's Committee on Mental Retardation; (2) MR 69, the committee's third report; (3) a publication by the Department of HEW on the mental retardation construction program; (4) selected laws relating to mental retardation, and (5) prepared statements and other information pertinent to the hearing that may be submitted before the record is closed. I also ask that the administration bill, when it is introduced, be printed in the record.

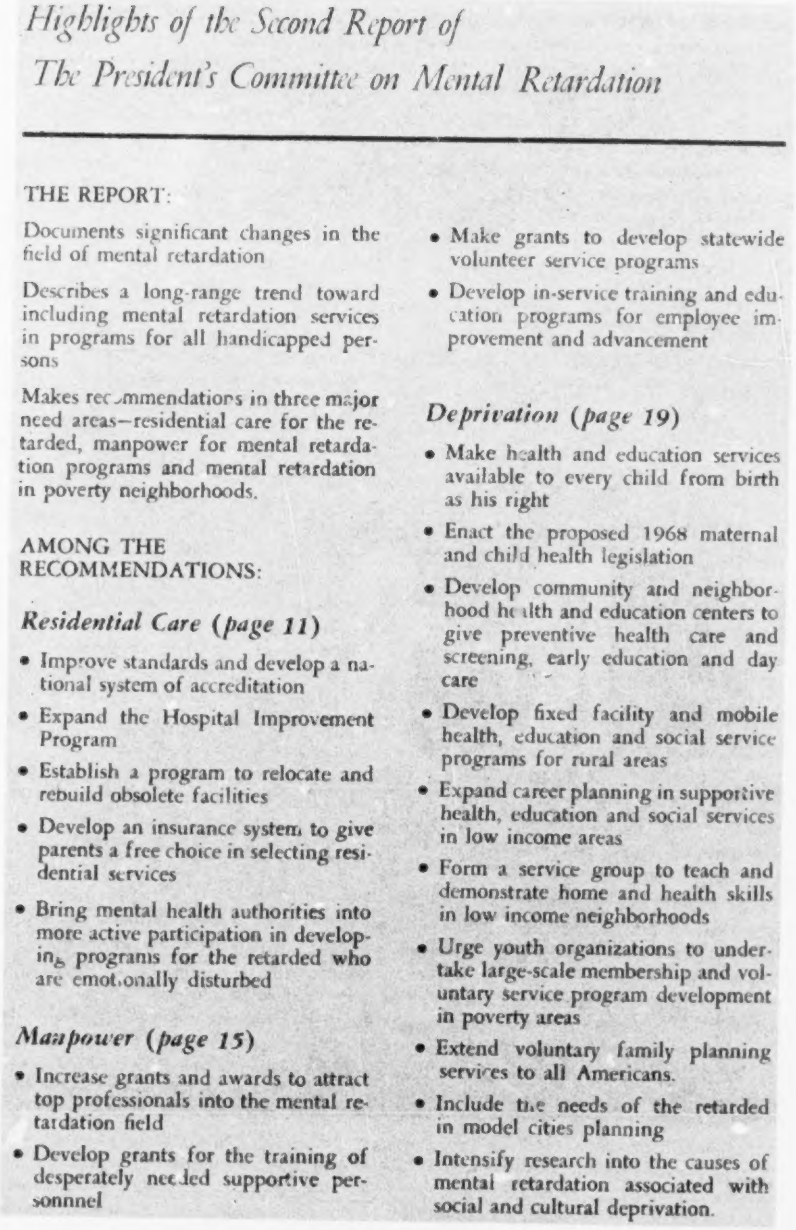


MR68

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

The Edge of Change

A REPORT TO THE PRESIDENT ON MENTAL RETARDATION PROGRAM TRENDS AND INNOVATIONS, WITH RECOMMENDATIONS ON RESIDENTIAL CARE, MANPOWER, AND DEPRIVATION



Highlights of the Second Report of The President's Committee on Mental Retardation

THE REPORT:

Documents significant changes in the field of mental retardation

Describes a long-range trend toward including mental retardation services in programs for all handicapped persons

Makes recommendations in three major need areas—residential care for the retarded, manpower for mental retardation programs and mental retardation in poverty neighborhoods.

AMONG THE RECOMMENDATIONS:

Residential Care (page 11)

- Improve standards and develop a national system of accreditation
- Expand the Hospital Improvement Program
- Establish a program to relocate and rebuild obsolete facilities
- Develop an insurance system to give parents a free choice in selecting residential services
- Bring mental health authorities into more active participation in developing programs for the retarded who are emotionally disturbed

Manpower (page 15)

- Increase grants and awards to attract top professionals into the mental retardation field
- Develop grants for the training of desperately needed supportive personnel
- Make grants to develop statewide volunteer service programs
- Develop in-service training and education programs for employee improvement and advancement

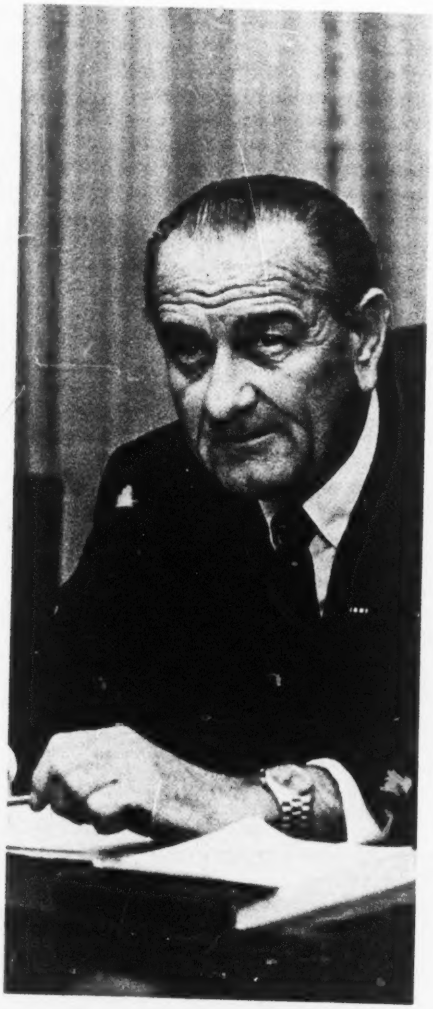
Deprivation (page 19)

- Make health and education services available to every child from birth as his right
- Enact the proposed 1968 maternal and child health legislation
- Develop community and neighborhood health and education centers to give preventive health care and screening, early education and day care
- Develop fixed facility and mobile health, education and social service programs for rural areas
- Expand career planning in supportive health, education and social services in low income areas
- Form a service group to teach and demonstrate home and health skills in low income neighborhoods
- Urge youth organizations to undertake large-scale membership and voluntary service program development in poverty areas
- Extend voluntary family planning services to all Americans.
- Include the needs of the retarded in model cities planning
- Intensify research into the causes of mental retardation associated with social and cultural deprivation.

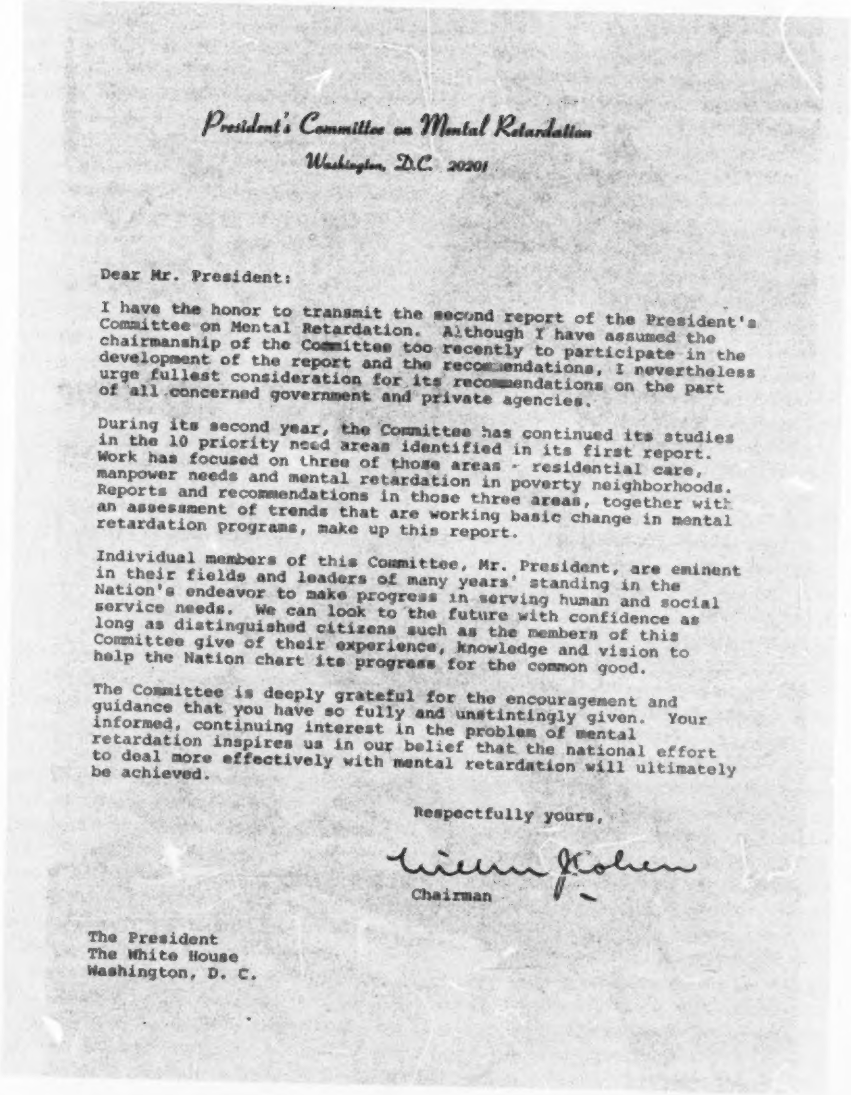
MR68

The Edge of Change

THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION



We cannot rest as long as there is one child
who becomes retarded through our neglect,
one individual who lacks the care he needs
because of our indifference,
one person who fails to reach his potential
. . . no matter how limited.
—LYNDON B. JOHNSON



President's Committee on Mental Retardation
Washington, D.C. 20201

Dear Mr. President:

I have the honor to transmit the second report of the President's Committee on Mental Retardation. Although I have assumed the chairmanship of the Committee too recently to participate in the development of the report and the recommendations, I nevertheless urge fullest consideration for its recommendations on the part of all concerned government and private agencies.

During its second year, the Committee has continued its studies in the 10 priority need areas identified in its first report. Work has focused on three of those areas - residential care, manpower needs and mental retardation in poverty neighborhoods. Reports and recommendations in those three areas, together with an assessment of trends that are working basic change in mental retardation programs, make up this report.

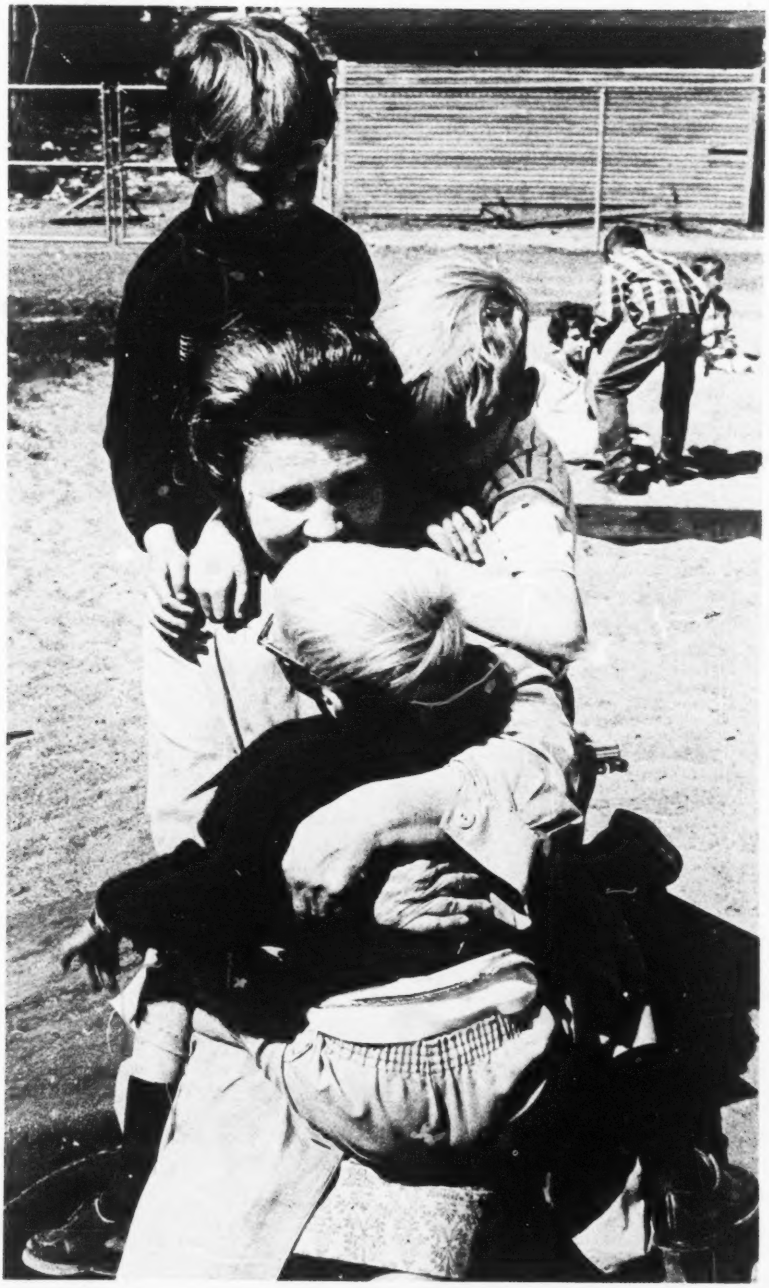
Individual members of this Committee, Mr. President, are eminent in their fields and leaders of many years' standing in the Nation's endeavor to make progress in serving human and social service needs. We can look to the future with confidence as long as distinguished citizens such as the members of this Committee give of their experience, knowledge and vision to help the Nation chart its progress for the common good.

The Committee is deeply grateful for the encouragement and guidance that you have so fully and unstintingly given. Your informed, continuing interest in the problem of mental retardation inspires us in our belief that the national effort to deal more effectively with mental retardation will ultimately be achieved.

Respectfully yours,

Wilbur J. Cohen
Chairman

The President
The White House
Washington, D. C.



The Edge of Change

THE enduring change that brings new directions and meanings into life comes on like a new day: not all at once, but in a growing definition of shapes, a stirring as men awake, and finally a growing fullness of light and movement.

Thus has basic and meaningful change been coming into the lives of the nation's millions of mentally retarded in this decade.

There is a long way to go and much to do before the new day for the retarded is full. But the dawn is now far enough advanced to distinguish much that is new and many of the directions that progress must take.

Three developments are bringing on the new day for the retarded:

- **POPULAR AND PROFESSIONAL ACCEPTANCE** of the mentally retarded as human beings who can grow and learn to make the most of their abilities.

- **AGENCIES' REAPPRAISAL** of their missions and methods in light of new and different human needs to be served. This reevaluation, often painful, is bringing new patterns of social action and citizen participation in community affairs.

- **RECOGNITION OF MENTAL RETARDATION PROGRAM DEVELOPMENT AS AN INESCAPABLE PART OF THE RESPONSE TO CRITICAL NATIONAL ISSUES** such as poverty and deprivation, city planning and renewal, manpower training and use, education policy, population study and human resources planning.

Ushering in the new shape of life for the retarded are hundreds of programs and projects. Federal government programs grounded in landmark legislation enacted by Congress during your administration, President Johnson, have brought major program advances in a field of human need seriously neglected before. This federal action — such as construction of university-affiliated training facilities, mental retardation research centers and community mental retardation service facilities — has spurred important beginnings nationwide in meeting the evident needs of the mentally retarded.

As a result, social action, career and research possibilities never before available have opened up.

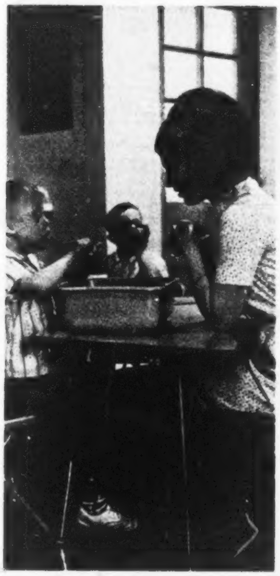
And mental retardation has been brought into the mainstream of citizen concern as a national problem that every American can help meet in his own community.

Real change announces itself in new ways of tackling problems and needs at the grass-roots level. There are now hundreds of such new-look activities throughout the country. The following pages present a sampling.

Diagnosis, Study, Treatment: A Problem of Availability

Interest and expertise in mental retardation are still scarce in health, education, social work, psychology and other professions. As a result, competent, helpful guidance for retarded children and their families continues to be a desperate need.

Progress is coming as specialists recognize that mental retardation is a many-sided problem and that its "cure" comes only in the fullest possible development of individuals' particular abilities. Prevention demands massive public education and public involvement as well as top professional work. These needs are now producing such innovative programs as:



- DIAGNOSTIC, STUDY AND TREATMENT CENTERS. These bring together teams from many fields. The U.S. Children's Bureau has taken the lead in starting a national network of such centers. Some states are now building their own. The aim of these centers is to put comprehensive diagnostic and study centers within reach of every family.

- REGIONAL SERVICE PROGRAMS. Here the aim is to make care, education, training and other service programs for the retarded conveniently available to every family. A few states now have a network of such centers.

- COMMUNITY CENTERS. These are on the front line of community health and social services. Some serve only the retarded, but increasing numbers work with all handicapped conditions. Their sponsorship and patterns of operation differ. Some are under-one-roof cooperatives of community public and private agencies. Others coordinate the efforts of groups of agencies.

- SPECIAL MEDICAL AND ALLIED PROGRAMS. Of many kinds, these seek to meet specific needs that—usually—have been overlooked before. Examples:

  - A southwestern city's mouth care training and dental treatment program for every retarded child in its area.
  - Mobile unit diagnostic programs in some rural areas.
  - Trained home health aides to relieve mothers of severely retarded children of their constant care.
  - Homemaker services for families with a retarded infant.

- PUBLIC INFORMATION PROGRAMS. The great number and variety of these highlights the widespread public interest generated by the problem of retardation.

The 3-year public service campaign on mental retardation coordinated by the Advertising Council brought over $30 million in contributed space and time from newspapers, magazines, radio and television stations and display advertisers.

State and community campaigns to spur public awareness of retardation and its causes have been conducted in nearly every state by such groups as the U.S. Jaycees, Civitan International, United Commercial Travelers, women's club federations, service fraternities and sororities. These activities have often been tied to measles vaccination campaigns, better nutrition drives and other mental retardation efforts.

Residential Care: A Road to Main Street

Everybody's picture of the "bad old days" in mental retardation is the large warehouse giving custodial care to the forgotten retarded. That picture, tragically and disgracefully, is still true about many of the nation's public and private institutions for the retarded (*see special report beginning on page 11*).

At the same time, however, dedicated staffs, imaginative state leaders and federal encouragement for innovation are spurring the development of institutional programs of startling freshness and vision.

- COMMUNITY GROUP LIVING PROGRAMS. These are making it possible in some states to move significant numbers of people *out* of institutions and into community living. Making the move are two kinds of institution residents--trained workers starting on jobs in the community and semi-independent persons able with minimum supervision to live in the community. This trend has brought major growth in community foster care programs for the retarded.

- BEHAVIOR MODIFICATION. Improvement in the hyperactive, sometimes self-destructive behavior often found in the severely retarded has made learning and social growth possible for the first time for many retarded persons. These capabilities in the severely retarded were undreamed of even by most experts until recently.

- "SPECIAL PEOPLE" PROGRAMS. These bring the care, compassion and hope of concerned citizens into the lives of individual retarded persons. They are vitally important, effective programs that operate on small budgets.

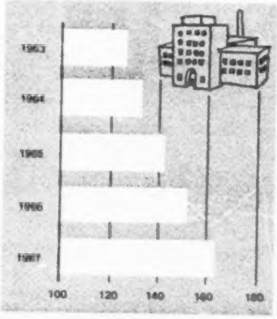
The Foster Grandparents Program gives this service opportunity to the elderly. High school and college students take part through the Student Work Experience and Training (SWEAT) Program. (Unfortunately, both these programs have been curtailed by budget cuts this year.)

Some institutions give service and training opportunities to VISTA volunteers. At least one institution has formed a Neighborhood Youth Corps unit of retarded residents.

Nearly every institution in the country has a group of community volunteers. These groups increasingly include high school and college students.

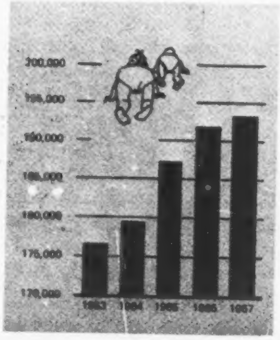
- INNOVATIVE RESPONSE-TO-NEED PROGRAMS. These are of many kinds. For example: Residence ward nurses in a midwest institution learned speech and physical therapy techniques in order to supply steady reinforcement to therapists' work during residents' on-ward hours. . . . A southern institution fitted a bus as a mobile classroom so that field trip experiences could be discussed on the spot before returning. . . . A west coast insti-

INCREASE IN NUMBER OF
PUBLIC INSTITUTIONS
FOR THE MENTALLY RETARDED 1963-1967



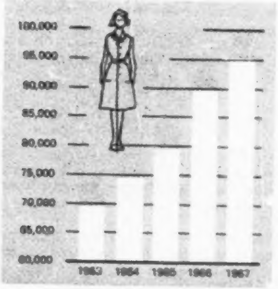
Approximately 50% have less than 1000 population; approximately 30% have more than 2000 population. Most institutions established since 1960 have less than 1000 population. Of the present 165 institutions, 33% have been constructed in the past ten years.[1]

INCREASE IN NUMBER OF RESIDENTS
IN PUBLIC INSTITUTIONS FOR
THE MENTALLY RETARDED 1963-1967



Reports indicate a significant increase in the severely retarded and the emotionally disturbed mentally retarded among recently admitted residents of these institutions.[3]

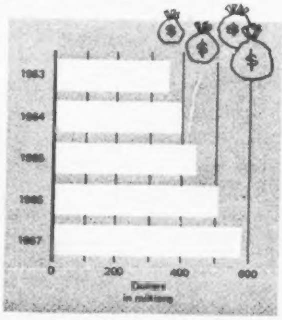
INCREASE IN NUMBER OF EMPLOYEES
IN PUBLIC INSTITUTIONS FOR THE
MENTALLY RETARDED 1963-1967



Although there was a 36.6% increase in number of employees during the period shown, the staff-to-resident ratio changed very little. There was still in 1967 a need for 50% more staff to meet the minimum ratios established by The American Association on Mental Deficiency.

Staff-to-resident ratio, 1963, was 1: 2½; and staff-to-resident ratio, 1967, was 1: 2⅓.[2]

INCREASE IN OPERATING COSTS
IN PUBLIC INSTITUTIONS FOR
THE MENTALLY RETARDED 1963-67



Although operating costs increased by more than 63% in this period, staff increased by only 36%. There is presently a need for 50% more staff to meet minimum standards of The American Association on Mental Deficiency. Since wages and salaries are more than 70% of the institutional budget, it is apparent that total increase has not kept pace with need.[4]

tution uses behavior-modification to teach one group of residents how to work with another, more severely retarded group to improve the latter's behavior. . . An occasional community is now developing programs to meet the special needs of the adult retarded, a group often overlooked. Also being tackled in some programs are the needs of the multiply handicapped retarded individual. . . A community service group in one eastern state works with mentally retarded offenders committed to the state penitentiary. (A national sample of 90,000 prison inmates was recently found to include nearly 8,600 mentally retarded persons.)

Education and Day Care: More, Earlier, Better

Discoveries of far-reaching significance have been made in recent years in the field of learning.

Studies have found that the period of most rapid learning comes years before school begins. The range of an individual's intelligence is largely set in earliest childhood. It can be blunted in those same early years by a limiting, harsh, negative environment.

It has also been found that traditional education methods faced many children with problems that their special learning handicaps make difficult or impossible for them to surmount.

Education and day care for the intellectually handicapped have thus grown up as innovation-minded, probing fields. Some of the new look programs now under way in these fields include:

● PRE-SCHOOL CLASSES. These aim to give the retarded child a running start when his potential for learning is highest. Another goal is to prevent functional retardation. Programs range from infant stimulation projects to school entrance readiness classes.

● MACHINES, SPECIAL MATERIALS AND TECHNIQUES. Samples:

■ A multi-station electronic laboratory gives programmed instruction to varying-sized groups simultaneously. An aide supervises each group. Teachers concentrate on children needing individual attention.

■ Audio-visual presentations and role-playing supplement field trips in a western program that helps retarded children build a sense of self-worth.

■ A reading readiness program built on picture-word associations produces results even with severely retarded pupils.

■ A community center produces film strips on personal hygiene and grooming for the trainable retarded.

■ A state university produces an educational television series for the retarded in every primary and intermediate class in the state.

■ A private organization center devised simple pre-primers which retarded children in a reading readiness program compiled from their personal experiences.

● SPECIAL INSTRUCTIONAL PROGRAMS. These are as varied as the needs that imaginative special educators see. A midwest public school system teaches concepts of language and systematic thinking to pre-school children who have language difficulties. Aim is to overcome retardation caused by social deprivation. . . Several urban school systems have driver education programs for the educable mentally retarded. . . Another midwest system provides a "continuum of care" curriculum that begins in the pre-school years and continues into adulthood for both educable and trainable mentally retarded.

● **DAY CARE TRENDS ARE TOWARD MORE PROFESSIONAL PROGRAMS,** away from babysitting and "just play." Among developments:

■ One western state has developed an accreditation program to upgrade the competence of day care center administrators, staffs and aides. Three universities cooperate by offering classes.

■ Public health nurses in a southern state give school health services in day care centers for the retarded.

■ The office of mental retardation in an eastern state aids voluntary organizations' inner city day care activities to help counter functional retardation. . . An institution in the same state offers summertime enrichment programs for the children of migrant workers.

● **SPECIAL EDUCATION INSTRUCTIONAL MATERIALS CENTERS.** Established by the U. S. Office of Education in cooperation with universities, these centers spur a flow of information and guidance to special education teachers of the retarded and other handicapped. Fourteen centers are in operation.

Vocational Training, Employment: People and Jobs Fitted Together

Vocational training and employment of the retarded have proved out in dollars and cents as well as in the intangibles of pride and dignity.

Lifetime incomes of vocational rehabilitation trainees, according to a Department of Health, Education, and Welfare study, average 16 times the cost of the training.

The nearly 5,000 mentally retarded workers in 30 federal government agencies receive a higher percentage of outstanding performance ratings than any other government workers.

A national food service company that has employed retarded workers for more than 5 years found in a comparative performance study that retarded workers stay in their jobs over twice as long, do their jobs well three times as often, and get along with co-workers far better than non-retarded workers do.

Every achievement, however, reveals new needs to be met, new horizons to be explored. Among new-look programs are:

● **JOB SIMPLIFICATION AND REDESIGN.** These are now making it possible to train retarded workers as data processors, electronic component assemblers, bank clerks and offset press operators.

● **INTENSIVE JOB PREPARATION AND PLACEMENT PROGRAMS.** One midwest state's program joins five agencies in an 8- to 9-month preparation of long-time institution residents as nurse's aides, housekeepers and food service workers, finds homes for them in communities and places them in jobs.

● SPECIAL RESIDENTIAL TRAINING PROGRAMS. These programs offer Monday through Friday residential center training opportunities to retarded persons who cannot conveniently take training on a day basis.

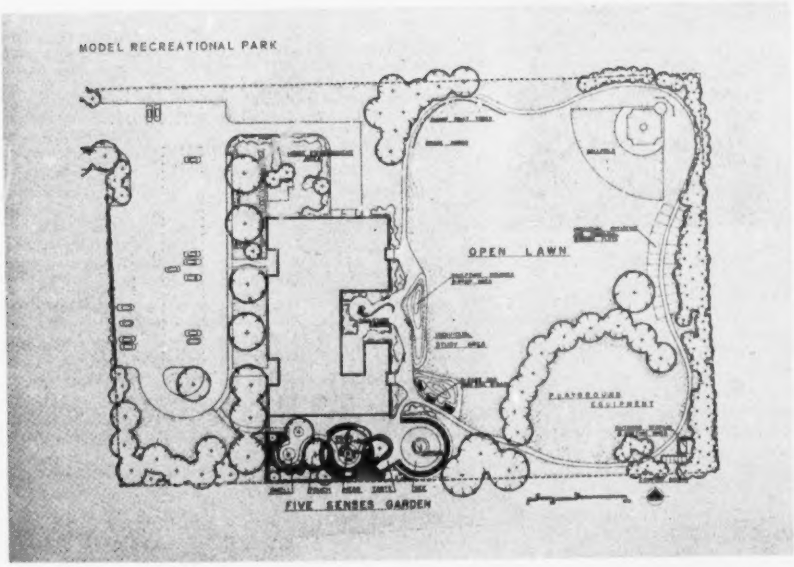
Planning, Programming, Manpower Development: What Makes the Action Go Forward

Until recently, the design and administration of programs for the mentally retarded was largely confined to programs in residential institutions.

The emergence of community based services during the past decade has radically altered old patterns. Today, the planning and administration of up-to-date programs for the retarded is a highly complex activity that reaches into every area of community endeavor. It joins many kinds of resources to bring better service to the retarded and is highly innovative.

Among examples of new-look program design, administration and resource development activities in the retardation field are:

● A midwest state's *interagency case information service* tied into state university computer center.


MODEL RECREATIONAL PARK
OPEN LAWN
BALLFIELD
INDIVIDUAL STUDY AREA
PLAYGROUND EQUIPMENT
SMELL
TOUCH
HEAR
TASTE
SEE
FIVE SENSES GARDEN

- *A cooperative planning and programming project for a sparsely settled area* of thousands of square miles, being carried out by four western states. Communications heart of the program is a network of intensively trained citizens whose strategic locations make them logical referral and feedback resources.

- A central state's interagency retardation planning group has developed and begun implementing *detailed service planning models* for work with the socio-economically disadvantaged teenaged girl, the pregnant woman in a poverty area and the pre-school child in deprived areas.

- The National Association for Retarded Children established during the past year the first national organization of youth united to serve the retarded. State units are being organized rapidly.

- A midwest city's association for retarded children and anti-poverty program *jointly planned and developed a center for handicapped children in low income neighborhoods.*

- *Workshops, training institutes, information exchange and other in service developmental activities* are becoming widespread. Growing numbers of programs use closed circuit television for staff training as well as case study. . . . A southern regionwide program spurs training and experience exchange among retardation specialists and institution staffs. . . . An eastern state institution offers a course to qualify attendants for high school equivalency certificates with resultant job advancement and increased pay.

- Aiming for one-to-one staff-patient ratios in programs for the retarded and other handicapped, an eastern state *trains supportive workers to assist specialists*, thereby freeing the specialists to concentrate on the major concerns their training has qualified them to handle.

What the New-Look Programs Mean

Citizen action to focus attention on a specific health or social problem has been a potent force behind dramatic advances in American health, education and social services.

Such action has led in two generations' span to almost total conquest in the United States of tuberculosis, polio, diphtheria and measles. It has spurred wide popular participation and technical progress in overcoming mental retardation, mental illness, heart and circulatory disorders, crippling neurological conditions and cancer. It is now awakening the nation to the profound interrelationships of man and his environment.

Almost everything we have been learning in this explosive century, however, has shown us that no problem exists in a vacuum.

Solutions to Problems A and B may be found in a study of apparently unrelated Problem C.

Effective diagnosis, study and treatment of any condition now requires the cooperative knowledge and skills of many people from many fields.

At the same time, our communities' health, education and social needs—particularly in low income areas—have become so great, and the resources to meet them so inadequate in their present applications, that fundamental revision in the delivery of community services has become a critical necessity.

Leaders in the field of mental retardation must face up to this challenge. The campaign to prevent mental retardation and help the mentally retarded utilize their abilities fully is entering a new phase.

Because resources of money and people are short and because human needs are so deeply interrelated, people and organizations interested in specific handicapping conditions will need to work together increasingly.

The development of all-inclusive approaches to handicapping conditions will promote more effective services for retarded individuals than can be found in most communities today.

Such approaches would end the tragic limbo into which the emotionally disturbed retarded have so often fallen.

They would end the frequent neglect of individuals having unusual retardation-allied conditions such as autism.

Comprehensive approaches would particularly make it possible to tackle the awesome amount of mental retardation that has social and environmental causes. This retardation is frequently neglected in today's largely biomedically oriented research and treatment programs.

The time has come for workers with the retarded to surmount their fears of submergence and neglect in comprehensive programs for the handicapped. Substantial grounds have often existed for such fears . . . and still do in many programs. But important changes in knowledge and attitudes about the retarded are combining to make enlightened action possible.

The mistaken notion of retardation as an irreversible, unchangeable condition is at last giving way in a score of fields. Replacing this long-frozen view of retardation is a mounting involvement and excitement among scientists, health specialists, educators, psychologists, social workers and therapists.

This new attitude is bringing attention, respect and action programs to the field of mental retardation. If wisely cultivated, it will assign retardation as important a priority in comprehensive service planning and programming as that given to any other handicapping condition.

The protection of the interest of the retarded over the next decade, then, will probably be a matter of two related endeavors.

We will need to cultivate the excitement about the possibilities of making important progress in preventing and overcoming human functional disorders.

And *all* groups and individuals concerned about such disorders will need to insist that *every* handicapped individual get all of the help he needs to grow to the fullest realization of his own abilities and potential.

★ ★ ★ ★

Last year, this Committee pointed out 10 areas in which major action in furthering the national campaign against mental retardation was needed. During the year since submitting its first report, the Committee has focused major effort on studies in three of those areas—residential care of the retarded, manpower for programs working with the retarded, and poverty-linked retardation. Reports with recommendations in these areas follow.

CSRC
CSRC

MR PRIORITY REPORT:

Residential Care for the Retarded

MANY of the nearly 200,000 residents in state institutions for the mentally retarded live in disgraceful conditions that the states' own regulatory agencies would not tolerate in privately operated facilities for anyone.

Moreover, the facilities in which these retarded persons live are in many cases in a state of decay.

The average age of institution buildings is 44 years. Some have reached the century mark. At least 50 percent are functionally inadequate for the care, growth, learning and rehabilitation programs that can be successfully carried out with the retarded.

The reasons are not hard to find.

Many states' institutions are administrative stepchildren. They are often located in remote places, far from population centers, according to a long-prevailing view of the retarded as mistakes of nature to be put out of sight.

They are poorly budgeted: the national average expenditure per person per day—with *all* costs, both direct and indirect, figured in—is just $7.60, and actual amounts range down to just over $3.00 in some states.

Staffs are often underpaid, underqualified and without reasonable hope of having better working conditions or career advancement. Institution locations and pay scales make recruitment of trained manpower difficult. Archaic, uneconomical administrative practices, born of the low-budget necessity to "make do," have hardened into tradition at many institutions.

Seen in this perspective, the accomplishments of some institution administrators and staffs in developing fresh, innovative programs (see page 5) appear near miraculous.

The closest approach to development of standards for residential facilities for the retarded has been made by the American Association on Mental Deficiency with its institutional evaluation program. The AAMD effort, helpful though it has been in guiding many institutions' improvement activities, chiefly covers the traditional large, hospital-oriented type of residential program, however, and contains little guidance on day-to-day care.

Taxpayers pay over a half-billion dollars a year to operate these so-often inadequate facilities for residential care of the retarded. In all too many cases, it is half a billion dollars paid to perpetuate outmoded, inhumane "warehousing" of human beings.

The dilemma of how to improve the nation's institutions for the mentally retarded is a tough and tangled one. The essence of the problem is what to do about buildings, budgets, programs and populations that have existed in neglect and decay for many years with little or no thought being given to their needs by either state officials or the public.

Renovation of existing buildings is often too costly to undertake. But states hesitate to abandon such buildings because of the investment put into them. Finding another use for them is usually difficult because of their isolated location.

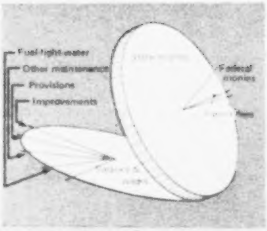
A look at institution budgets can be like an expedition into a hidden land that time forgot. Needs that were great in 1930 may not yet have been constructively studied and responded to. The hundred different ways of using residents' unpaid labor to flesh out penny-pinching personnel budgets would appall labor and management specialists.

Housed in inadequate buildings and chained by inadequate budgets, many institutions, moreover, cannot control the size or kind of population they must care for. Nationwide, there are thousands of mildly retarded individuals, "behavior problems" and "slow learners" in residential facilities for the retarded who should not be in these institutions.

THE RESIDENTIAL CARE DOLLAR

HOW IT IS SPENT

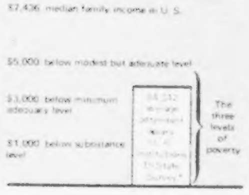
[illegible]



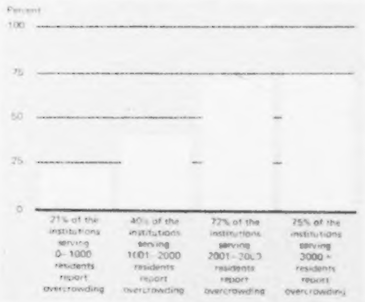
WHERE IT COMES FROM

Federal Sources	[illegible]
Education of Handicapped Children Grants	[illegible]
Hospital Improvement Grants	[illegible]
Hospital Inservice Training Awards	[illegible]
Foster Grandparent Program	[illegible]
Student Work Experience & Training Program	[illegible]
Maternal Health and Mental Retardation Services	[illegible]
Title XIX, Social Security Act	[illegible]
Parent Fees	[illegible]
State and County Monies	[illegible]

ATTENDANT SALARIES RELATED TO POVERTY LEVELS

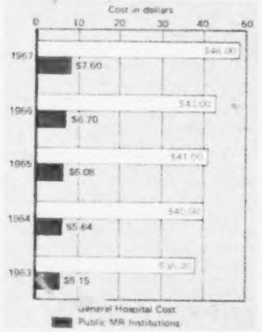

$7,436 median family income in U. S.
$5,000 below modest but adequate level
$3,000 below minimum adequacy level
$1,000 below subsistance level
[illegible] average attendant salary [illegible] institutions [illegible] State Survey
The three levels of poverty

OVERCROWDING IN PUBLIC INSTITUTIONS FOR THE MENTALLY RETARDED



The larger the institution, the more likely it is to be overcrowded.

COMPARISON OF COSTS:
GENERAL HOSPITALS VERSUS PUBLIC
INSTITUTIONS FOR MENTALLY RETARDED
PER DIEM COSTS 1963-1967



The cost of general hospital care increased $10.70 during the 5-year report period while the cost of residential care for the mentally retarded increased only $2.45 during the same period.

Sources: Inside back cover

Thousands of severely retarded individuals are on waiting lists trying to get in. Institutions' budgets, administrative channels and ties with other agencies are too often insufficient.

The need is now too great and too long neglected to be solved by the states alone. Massive federal intervention to spur the improvement of present facilities and the development of new, up-to-date self-renewable systems for the residential care of the mentally retarded is imperative.

The recommendations that follow offer a program for beginning the job in a constructive way that will make as much use as possible of existing facilities and resources.

1. Control of the quality of public, non-profit and private residential care for the retarded is essential.

We recommend, therefore, that the appropriate professional and voluntary organizations, with support from the federal government, take immediate steps to improve the standards for residential care of the retarded and simultaneously develop a system of accreditation of residential care programs and facilities for the retarded.

2. The federal government's Hospital Improvement Program has elicited imaginative new approaches to delivering residential care in state institutions.

We recommend that this program now be expanded to effect major change by:

A. Greatly increasing funds, with the provision that every state institution for the retarded have opportunity to participate.

B. Making awards on the basis of a state plan for bringing present institutions up to acceptable standards and the development of community-based residences as alternatives to institutions.

C. Relating awards to the size, budget, and needs of the institution.

Particular effort in this connection must be made to meet the unmet needs of the severely and profoundly retarded. Accommodations and care for them are inhuman in many institutions.

3. The use of outmoded, mass-housing buildings must be ended. Industry has rarely hesitated to abandon and replace obsolete plants; states should be no less firm in developing up-to-date facilities. A new geographic distribution of modes and forms of residential care services—including group homes, residential vocational training centers, nurseries and specialized nursing homes—is badly needed.

We recommend, therefore, that a new part be added to Public Law 88-164 to establish a construction program for relocating and rebuilding obsolete residential facilities.

Safeguards must be included to insure that future institutions do not perpetuate the mass housing and programming patterns of the past, and that the construction be planned for easy modification as new techniques and needs are found. The planning should be carried out in consultation with architects, urbanologists, demographers, community developers and other specialists in environmental sciences.

4. Hospital In-Service Training Program grants should be greatly increased to include significant training for both leadership and direct service personnel in residential care facilities.

5. Public and private social services for children and adults are related to residential care for the retarded in two ways: one, they can suggest alternatives to residential care; two, they have the competency to counsel families during their times of greatest stress —such as the time of deciding to seek a child's admission to an institution, or that of returning a retarded person to community living.

We recommend that federal, state and local welfare agencies, both public and private, clearly identify a portion of their resources for welfare services to the retarded and their families.

Such services include casework, adoption, homemaker services, foster care and day care.

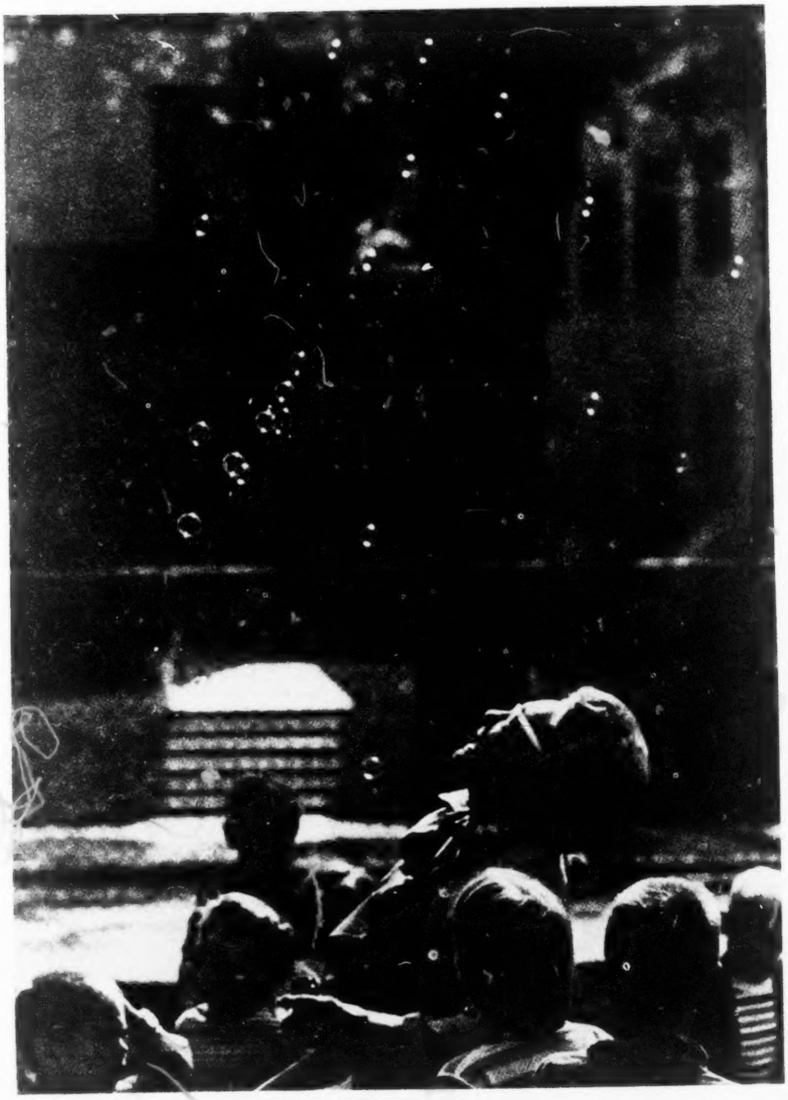
Immediate strengthening of child welfare services to the retarded through expert staffing, consultation and training is an essential component of this recommendation.

6. We recommend that a federally supported insurance system be established to enable a free choice in selecting residential services.

The exercise of free choice in the selection of an institutional home for a retarded individual will bring to the residential care field the improvement motivation of free, competitive enterprise.

7. In order to provide a viable choice, we further recommend that a system of loans or grants be developed to assist private non-profit and proprietary organizations to establish alternative forms of residential care for the retarded, such as hostels, group homes, nurseries, residential vocational training centers, nursing homes and extended care facilities.

8. State and local mental health authorities and the National Institute of Mental Health should take active leadership in developing services and programs for emotionally disturbed retarded persons in residential care or community programs.



MR PRIORITY REPORT:

Manpower To Serve the Retarded

THE time has come for systematic action to overcome chronic shortages of trained persons to work with the mentally retarded.

The shortages are felt in every kind of program for the retarded.

There are too few physicians, nurses, social workers and psychologists to give needed diagnostic and evaluation services. There are too few teachers trained to work with the retarded in the schools, too few therapists to work with them in community and residential care programs.

Less heard about, but equally critical, there are too few counselors and foster parents, too few foster grandparents and student workers, aides, too few volunteers.

Every kind of service with the retarded is in short supply.

At the same time, however, there is too much hand-wringing in the mental retardation field about specialist shortages and too little being done to find and develop supportive staff members to assist specialists.

The manpower problem in mental retardation is thus a double-barreled one. More workers, both specialists and supportive personnel, are needed. But also needed are searching studies to develop ways of extending specialists' efforts through the imaginative use of trained supportive manpower in all program areas.

Long a neglected career area, the mental retardation field is now pulsing with interest and challenge. Findings in human learning problems have brought special education to prominence and challenged the interest of students and teachers. Discoveries in genetics and biochemistry are making retardation research one of the brightest new frontiers of scientific exploration. Work simplification and job redesign studies have been spurred by findings about the increasingly more significant jobs that trained retarded workers can handle.

Meantime, large numbers of unskilled or semiskilled persons are entering the U. S. work force and the mainstream of the nation's economic life for the first time. Supportive service occupations offer an ideal route for many such workers into prideful and important careers. The nation's service organizations and agencies, including those working with the retarded, should not lose the opportunity to tap this resource through bold new programs of training and neighborhood involvement.

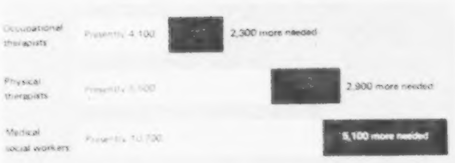
In the broad context of a great need for the services of many people and great opportunity for career growth in work with the mentally retarded, we make the following recommendations directed to manpower planning, development and use.

1. **We recommend that increased effort be made to attract scientists and professional specialists in education, the medical and behavioral sciences and related fields into research and service in the field of mental retardation. U. S. Department of Health, Education, and Welfare grants, scholarships and awards should be greatly expanded in support of this effort.**

Private organizations and foundation sources of support should also be sought and involved, particularly in researching and developing innovative uses of specialist manpower in serving the retarded and other handicapped persons.

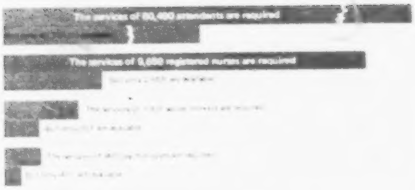
2. To increase supportive service personnel in mental retardation programs, **we recommend that existing grant programs such as the New Careers and**

CURRENT NEEDS* VERSUS SUPPLY IN THREE PROFESSIONS*

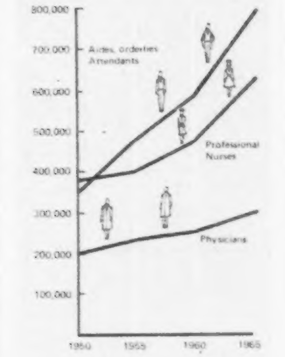


*Estimates for the 7,000 hospitals registered with the American Hospital Association are based on returns from 5,000. This is national data and [illegible] wider needs than just in the mental retardation field.

CURRENT STAFF SHORTAGES IN PUBLIC INSTITUTIONS FOR THE MENTALLY RETARDED

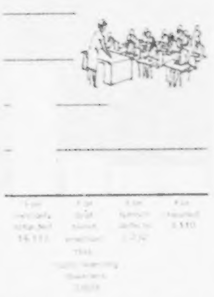


MAKING BETTER USE OF MEDICAL MANPOWER



Supply of physicians has risen little in recent years, but increased use of aides, attendants and nurses has made medical services go further.

TEACHERS NEEDED* FOR
SPECIAL EDUCATION IN THE SOUTH**
AN EXAMPLE OF MANPOWER SHORTAGE



*Estimates by state directors of special education and superintendents of state residential schools or hospitals, projected to [illegible] with total of needs shown to be 28,[illegible]

**States are Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, West Virginia.

Sources: Inside back cover

Neighborhood Youth Corps programs be expanded and new grant programs be made available through the Departments of Labor and Health, Education, and Welfare to recruit, train and place supportive workers such as teacher aides, nurse's aides, social casework and family service aides, and attendants in mental retardation services.

These grants should be administered primarily as work training and employment grants and should be made particularly available to low income applicants. The place of training and employment should preferably be clinics, schools (including public school special education classes) and centers serving the needs of the retarded in the trainee's neighborhood.

3. **We recommend a sustained effort on the part of all agencies operating programs for the retarded and other handicapped to attract into work with the retarded those qualified workers who may need only refresher training or slight retraining to return to work in service professions.**

A great potential in this area exists in nurses, therapists, teachers and other professionals who are not working during their family-raising years.

4. To expand mental retardation services with existing and potential manpower resources, **we recommend that professional groups recognize and extend professional acceptance to supportive personnel who work with their members.**

We also recommend that professional specialists and their associations evaluate specialists' functions with a view to transferring as many of those functions as possible to trained supportive workers.

We further recommend that professional groups reassess in light of the preceding any restrictions which they now place on the use of nonprofessional support personnel and reduce those restrictions to a minimum.

We urge in this connection also that higher education institutions review curricula to assure that courses reflect current thought on specialist and supportive staff duties and responsibilities in services for the retarded.

5. To improve utilization of adult and youth volunteers and to develop volunteer service as a major mental retardation manpower resource, **we recommend that a Department of Health, Education, and Welfare grant program be made available to each state to set up, expand or modify a volunteer service program available to both tax-supported and private programs for the retarded.**

6. **We recommend that institutions, schools, centers and other facilities offering services to the retarded develop employee education and training programs for employee self-improvement and upgrading. The Departments of Labor and Health, Education, and Welfare should collaborate in helping make such programs possible through grants and development of training models.**

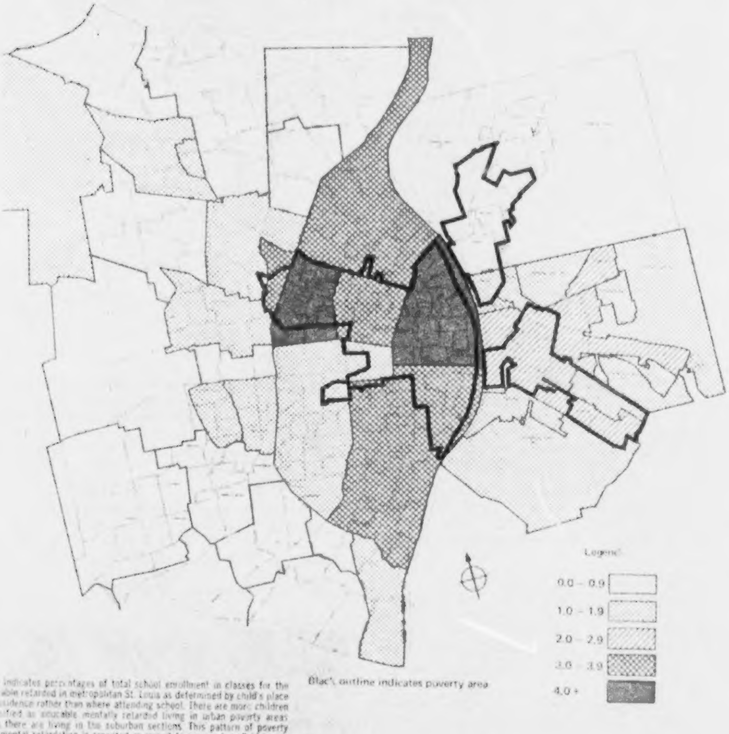
We also urge that supportive occupations in service to the mentally retarded be recognized as career opportunities, with adequate remuneration, on-the-job and other opportunities for learning new skills, and predictable lines of advancement and promotion for qualified aspirants.

7. To permit a wider sharing of knowledge and experience in the field of service to the retarded, **we recommend that the federal government develop and fund a program through which clinics, schools, residential care facilities and agencies could exchange specialist and supportive workers for mutual program benefit.**

8. To establish a common terminology for jobs and positions in programs serving the retarded, **we recommend that occupations serving the handicapped be defined in the Department of Labor's *Dictionary of Occupational Titles* and that the dictionary's definitions then become standard reference for workers serving the mentally retarded.**

In developing these definitions, the Department of Labor should also identify nonprofessional duties that have accumulated in the work of professional workers with the handicapped and suggest possible new service and support occupations in which these duties could be combined.

THE EDUCABLE MENTALLY RETARDED IN URBAN AND SUBURBAN AREAS



Black outline indicates poverty area

Map indicates percentages of total school enrollment in classes for the educable retarded in metropolitan St. Louis as determined by child's place of residence rather than where attending school. There are more children classified as educable mentally retarded living in urban poverty areas than there are living in the suburban sections. This pattern of poverty and mental retardation is repeated in map data prepared on Bridgeport, Los Angeles, Harrisburg and Seattle, and would be expected to be true of other major urban centers.[11]

Map developed by President's Committee staff, using school enrollment data supplied by school systems, 1968.

MR PRIORITY REPORT:

The Retarded Victims of Poverty

FACT:

Three-fourths of the nation's mentally retarded are to be found in the isolated and impoverished urban and rural slums.

FACT:

Conservative estimates of the incidence of mental retardation in inner city neighborhoods *begin* at 7 percent.

FACT:

A child in a low income rural or urban family is 15 times more likely to be diagnosed as retarded than is a child from a higher income family.

FACT:

Forty-five percent of all women who have babies in public hospitals have received no prenatal care. Avoidable complications of pregnancy, which are often the harbingers of crippling conditions in children, soar in this group.

FACT:

Incidence of premature births (among whom neurological and physical disorders are 75 percent more frequent than in full-term babies) is almost 3 times as great among low income women as among other groups of women.

FACT:

The mortality rate of infants born to low income mothers is nearly double that of infants born to mothers in other income brackets.

FACT:

The children of low income families often arrive at school age with neither the experience nor the skills necessary for systematic learning. Many are found functionally retarded in language and in the ability to do the abstract thinking required to read, write and count. An appalling number of these children *fall further behind* with the passing of each school year.

FACT:

Students in the public schools of inner city low income areas have been found in numerous studies to be from 6 months to 3 years behind the national norm of achievement for their age and grade. About three times as many low income children as higher income children fail in school. The child whose father is an urban laborer has only one chance in 3,581,370 of being named a National Merit Scholar; but the child whose father has a professional or technical position has one chance in 12,672.

FACT:

The rate of Selective Service System rejections for intellectual underachievement is 23 percent nationally and soars to 60 percent and more among groups whose members are largely from low income areas.

Mounting evidence is pointing to an intimate relationship between diet and mental and nervous disorders. Low incomes, economic stagnation, high rates of malnutrition and high incidence of disease, health problems and mental retardation are all found together in the nation's poverty neighborhoods, and even though they cannot yet be directly linked, more than coincidence is obviously at work.

To those of us with responsibility to advise on measures to combat mental retardation, the meaning of the known and apparent facts is clear: *the conditions of life in poverty—whether in an urban ghetto, the hollows of Appalachia, a prairie shacktown or on an Indian reservation—cause and nurture mental retardation.* We believe that attack on the fester points of poverty will also hit the causes of retardation in the nation's rural and urban slums.

We therefore support and urge all speed in the war on poverty at all levels, by both the public and private sectors of American life. Within that framework, and with a focus on preventing mental retardation as well as other handicaps, we make the following specific recommendations.

1. Since mental handicaps afflicting millions of Americans stem from neglect, deprivation and lack of stimulation during infancy and early childhood, **we recommend that all service agencies, both public and private, act now to make health and education services available as the right of every American child from birth.**

The need for such action presents itself in every part of our communities. It has reached crisis stage in the nation's low income areas.

We recommend passage and full funding of the maternal and child health legislation which you, President Johnson, proposed in your 1968 State of the Union Address to assure prenatal care to mothers and first-year medical care to children in disadvantaged areas.

We also urge all necessary steps to assure systematic attention to the medical screening, health care and developmental education of children prior to school-entry age. In the absence of such attention today, nearly irreversible perceptual and learning handicaps become deeply rooted in great numbers of children.

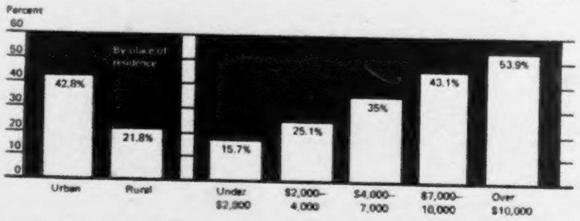
We recommend that the needed services be made available in urban and suburban areas through community and neighborhood health and education centers located for convenient access by all. These centers would initially furnish three kinds of services:

A. Preventive health care and systematic screening for health and developmental handicaps in children from birth to school-entry age; prenatal care and counseling for pregnant women.

B. Early developmental education beginning in the child's first year.

C. Day care for all children who need it, with the aim — as in Project Head Start — of promoting mental and social development from infancy onward and aiding parents to encourage each child's growth as an individual.

CHILDREN UNDER AGE 17 WHO HAD ROUTINE PHYSICAL EXAMINATION DURING A 12-MONTH PERIOD, 1962-63



Mental retardation and other handicapping conditions are often found through physical examination in childhood, but the isolated rural child and the child in the impoverished family is likely to miss examination. Handicapping conditions will therefore go undetected.[13]

Sources: Inside backcover

These centers would be financed cooperatively by the federal government, states and localities.

We do not minimize the great practical problems involved, but we believe that a network of centers in the highest-need areas can be started quickly. First requirement is a wholehearted commitment by community leaders, public and private agencies, professional groups and civic organizations to provide health and education services to infants and children as a first-priority investment in the nation's long-term health.

Representatives of the population living in the area to be served should be involved in the planning and leadership of each center so that the program meets area needs and continues to do so.

2. The problems of the handicapped in rural America urgently require special attention.

In our preoccupation with urban needs and problems, we have overlooked a crisis in rural health, social service and education that has been steadily growing more acute. This crisis was documented recently in the report of the President's National Advisory Commission on Rural Poverty, *The People Left Behind*.

The basic fact is that people in most rural areas are too few, too scattered and often too poor to support adequate services.

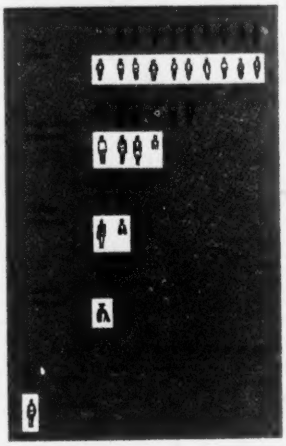
This problem needs to be attacked on a *regional* basis. As in the cities, existing resources should be brought together and applied.

We recommend that county governments, school districts, public health districts, medical and other professional societies and voluntary organizations (including such major rural forces as the American Farm Bureau Federation, the National Farmer's Union, the National Grange and other groups) **pool their resources to plan regional health, special education and social service facilities and programs that can handle the unique problems of specific rural areas through a combination of fixed-facility and mobile services.**

State and federal resources should be applied on a supplementary basis to assure adequate facilities and services in areas unable to finance or maintain them entirely.

We suggest that the United States Department of Agriculture's Extension Service, the Partnership for Health Program and the Comprehensive Rehabilitation Planning Program take leadership in promoting and coordinating the development of these regional programs. The population of each region to be

POVERTY'S CHILDREN: AN EXAMPLE OF EDUCATIONAL ATTAINMENT: NATIONAL LEVEL VERSUS APPALACHIA



ON THE NATIONAL LEVEL:

For every 10 pupils in first grade: 6 graduate from high school; more than 2 go to college; more than 1 finishes college.

BUT IN APPALACHIA:

For every 10 pupils in first grade: fewer than 4 graduate from high school; just over 1 goes on to college; fewer than 1 finishes college.[14]

Sources: Inside back cover

served should be represented in planning and operational groups.

3. The soaring incidence of mental retardation in the nation's disadvantaged areas calls for continued and intensified programs of education and rehabilitation for all persons whose skills and self-reliance could be improved.

We recommend, therefore, that federal assistance to state and local educational agencies for programs of education and rehabilitation serving those areas at all age levels be increased and significantly expanded.

4. The continuing national shortage of health, education and social service specialists makes the development of large numbers of supportive workers as "expanders" of specialists' efforts a crucial need.

We therefore urge that public and private agencies aggressively promote and develop career planning and opportunity in supportive health, educational and social services as an aid in supplying trained manpower for low income area programs, including those for the mentally retarded. Agencies' promotion of these opportunities should support adequate remuneration, on-the-job training activities and chances for advancement and promotion as part of supportive service occupation planning.

Potential supportive manpower resources abound in the low income areas themselves. These resources should be tapped to the fullest possible extent.

As part of this effort, we urge agencies and private industry to devise and conduct work training programs through which low income area residents can conveniently acquire the skills to work in supportive service positions. U.S. Department of Labor, Department of Health, Education, and Welfare and Office of Economic Opportunity grants should be available to assist in the development of these programs.

Built into the training programs should be services that will help make it possible for interested persons to be trained. Temporary child care, for example, should be furnished.

We also urge the formation of a community living service modeled on the U.S. Agricultural Extension Service.

The job of this service would be to recruit, train, assign and supervise highly skilled men and women in instruction and demonstration activities in homemaker, community hygiene and personal health skills in low income neighborhoods. A significant proportion of the service members should be from low income areas.

We suggest that the service be established as a federal government program so that uniform national standards and a pride in nationwide membership can be attained.

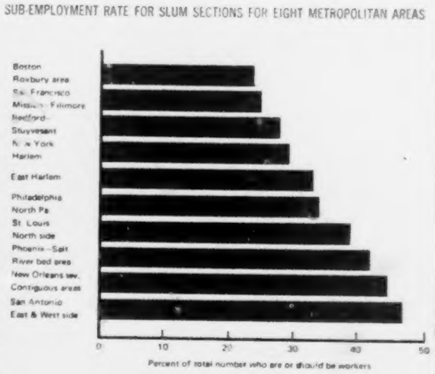
In addition, existing supplementary manpower programs that bring special groups into work with the handicapped should be expanded. Among these are the Student Work Experience and Training (SWEAT), the Foster Grandparent, and the Volunteers in Service to America (VISTA) programs. These low-budget projects have produced spectacular results both for those served and for their participants.

5. To help free young minds from the shackles of poverty and futility, **we urge the nation's voluntary and service organizations for children, youth, students and young adults to come to the aid of young people in low income areas, both urban and rural.**

Youth membership organizations such as the Boy Scouts and Girl Scouts, Campfire Girls, 4-H, Future Homemakers, Future Teachers, Future Farmers and religious youth groups might seek massive increase in members in low income neighborhoods. Leaders from those neighborhoods could be trained in hurry-up courses and modifications in membership qualifications and fees made as necessary to increase participation.

Volunteer service organizations for youth such as the newly formed and promising youth arm of the National Association for Retarded Children, Red Cross Youth and the various hospital youth auxiliaries could make major expansion of their activities into low income areas. These groups could make an especially critically needed contribution by furnishing the trained volunteer aides needed in neighborhood health and social welfare agencies, public health clinics, schools, day care centers and Head Start programs.

Such organizations should aggressively seek to involve civic and service organizations as co-sponsors



SUB-EMPLOYMENT RATE FOR SLUM SECTIONS FOR EIGHT METROPOLITAN AREAS

(Subemployment includes unemployment, underemployment and subminimum earnings.)
One out of every three slum residents who was already a worker, or who should and could become a worker with suitable help, was either jobless or not earning enough for living above the poverty level. The mentally retarded make up a significant proportion of the slum population, as demonstrated by the map on page 18. The mentally retarded are therefore strongly affected by such conditions as sub-employment and unemployment.[13]

Sources: Inside backcover

in these activities, especially to assure that such program needs as volunteers' transportation, needed uniforms and meals are furnished.

We also suggest that the voluntary service organizations for youth redouble their efforts to recruit low income area young people into community volunteer work, and that these organizations further work with the schools to develop a system through which junior and senior high school students could receive educational credit for volunteer service in the community.

6. A key factor in the futility of life in poverty is the accumulation of mischance and unwanted event.

One of the points at which the treadmill of futility can be stopped is in helping low income men and women plan the size of their families.

We recommend that family planning services and voluntary birth control assistance be made available through poverty area and other community agencies to help lower the alarmingly high rates of unwanted children and infant mortality in low income areas. We support your 1968 Health Message proposals on this subject.

We also recommend that the nation's schools promptly develop and offer a top quality program of instruction, beginning in the early elementary grades, in human biology and education for parenthood.

Over-all goal of this instruction would be to raise the quality of child and family life as well as arm young people with mature views of their future roles as responsible individuals, parents and heads of families.

7. Among the most difficult problems facing U.S. communities today are the elimination of slums, the design and construction of attractive low cost housing, and the planning and delivery of community health, education and social services.

We recommend that responses to the needs of the mentally retarded be incorporated in model cities and other programs that seek to improve present communities and design the communities of the future.

We also recommend that labor, industry and commerce be involved on a larger scale in the development and redevelopment of our communities to assure adequate standards of living and community human services for all citizens.

8. Ninety-five percent of the existing community facilities for the mentally retarded constructed under Public Law 88-164, Part C, are located in middle income neighborhoods.

We recommend that Congress amend P.L. 88-164, Part C, to give the Secretary of Health, Education, and Welfare authority to see that the facilities are located for best service to *all* of a given community's mentally retarded.

Requirements for matching funds should be made more flexible so they can be related to a

community's average income or even eliminated in very deprived areas.

9. Results are now beginning to come in from early childhood research and education programs being conducted throughout the country by universities, foundations and research laboratories. Without exception, their findings are that childhood programs can have long-term effect in preventing mental retardation linked to environmental lacks.

We therefore recommend intensification of research in the social and other behavioral sciences with the aim of isolating and defining the so-far unidentified social, environmental and cultural factors that cause or contribute to mental retardation.

10. Not all of the answers needed about the bonds between deprivation and retardation can be found through studies of human beings, however.

There is in existence a national network of centers developed for the purpose of man-related research which cannot be carried out in studies directly involving human beings. **We recommend that this network, the regional primate research centers, undertake major inquiries into the relationship to mental development of nutrition, infant stimulation, success-failure patterns and similar topics.**

Mr. President:

DURING the coming year we shall continue our studies of the three critical program need areas on which we have made recommendations in this report: residential care for the retarded, manpower development and use in mental retardation programs, and the mentally retarded victims of poverty and deprivation.

We expect to have further recommendations in these areas as our studies of programs, needs and trends progress.

We plan also to launch a major inquiry into the area of education for the mentally retarded.

In addition, you will be receiving special reports and papers on progress and needs in research on mental retardation and on a national information center. The latter is planned to bring together research and program information in the mental retardation field and to make that information conveniently and uniformly available to researchers and program planners nationwide.

Also directed to your attention will be a comprehensive monograph on the history, development, status and needs in residential care of the retarded. This monograph is the chief supporting document for the recommendations on residential care made in this report.

We will report to you from time to time on progress in several continuing studies.

One of these studies is attempting to define the economic impact and cost of mental retardation. The [illegible] of this study is to develop a body of economic information through which cost factors in mental retardation may be established for the guidance of agency planners, valid cost comparisons made, and viable program projections made.

Another study is developing guidelines for the use of model cities planners in incorporating designs for mentally retarded persons living and working in communities of the future.

All of these areas were identified in our 1967 report as having critical needs. Our work during the past year has carried forward from general de-

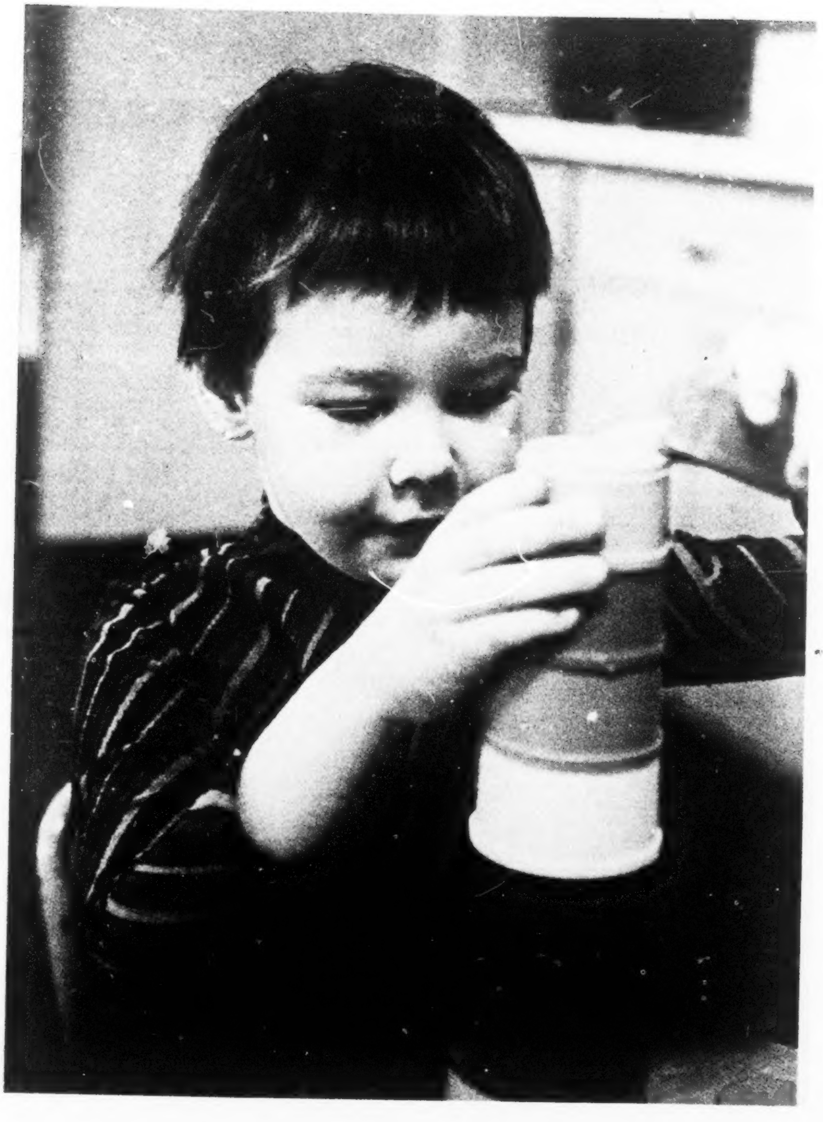
scription of those major need areas into the deep and detailed studies whose outcomes are reported in these pages or will reach you in later papers.

This 1968 report, as did its predecessor, suggests actions to combat mental retardation that can and should be taken at all levels of the nation by both public and private agencies. Retardation is a problem that can strike any family in the nation. Every individual, every agency can help to do something effective about the problem. Our fundamental belief is that the nation's ultimate success in the attack on mental retardation will be won by a broad cooperative effort in which professional specialists and citizen volunteers work together to combat retardation and its causes through programs in health, education, rehabilitation, community planning and organization, social service and research.

The field of mental retardation, with your steady support, President Johnson, has crossed the threshold of major change and advance. Some ways to foster growth and learning in even the most severely retarded have been found. The human cell's secrets of programming for the unborn are being pried out. The most critical period for learning has been found to be years before the time when formal education of children begins. Developing successful instruction for the retarded has enabled us to discover steps in the learning process that were unsuspected before. And analysis of work and work patterns in order to train retarded workers has shown that these workers can do more than previously thought and that the elements of even complex jobs can often be rearranged for effective performance by retarded workers.

It is crucial, therefore, that the momentum of interest and action developed in the problem of mental retardation in this decade be held and intensified.

We are grateful, Mr. President, for your continued personal inspiration and guidance to us and to the many others who are working on behalf of the retarded. The support of your Office is a key force in helping the nation bring on the new day when most mental retardation can be prevented and the remaining retarded individuals can be helped to be contributors to the common good.



Sources

[1,2,3,4] Adapted from **Mental Health Statistics, 1968,** a report by the National Institute of Mental Health.

[5] Adapted from **Patients in Mental Institutions, Part I, Public Institutions for the Mentally Retarded, 1965,** a report by the National Institute of Mental Health; and from **Charges for Residential Care of the Mentally Retarded, 1963,** a report by the National Association for Retarded Children.

[6] Adapted from data from (1) Interstate Clearinghouse on Mental Health, Council of State Governments: Arizona, California, Florida, Georgia, Illinois, Indiana, Kansas, Missouri, New Mexico, New York, Ohio, Oregon, Pennsylvania and Texas; and (2) Social Policy for the 1970's, from **Indicators,** May 1966, a publication of the U.S. Dept. of Health, Education, and Welfare.

[7] Adapted from **Mental Health Statistics, 1968,** a report by the National Institute of Mental Health; and from **Indicators,** 1966, a publication of the U.S. Dept. of Health, Education, and Welfare.

[8] Adapted from survey by American Association on Mental Deficiency, April, 1968; and based on rated bed capacity as reported by the institutions.

[9] Adapted from **Report on Allied Health Professions and Services, 1967,** a report by the National Advisory Health Council.

[10] Adapted from **Report of National Advisory Commission on Health Manpower, 1967.**

[11] "Services Required" figures computed from **Standards for State Residential Care,** as established (1964) by American Association on Mental Deficiency; and "Services Available" figures computed from staff census of **Patients in Public Institutions for the Mentally Retarded, 1965;** A report by the National Institute of Mental Health.

[12] Adaped from **The South's Handicapped Children,** a report of the Southern Regional Education Board, 1967.

[13] Adapted from **The People Left Behind,** 1967. The report by the President's National Advisory Commission on Rural Poverty.

[14] Adapted from **Education Advisory Committee Interim Report,** 1968, Appalachian Regional Commission.

[15] Adapted from **Manpower Report of The President,** 1967.

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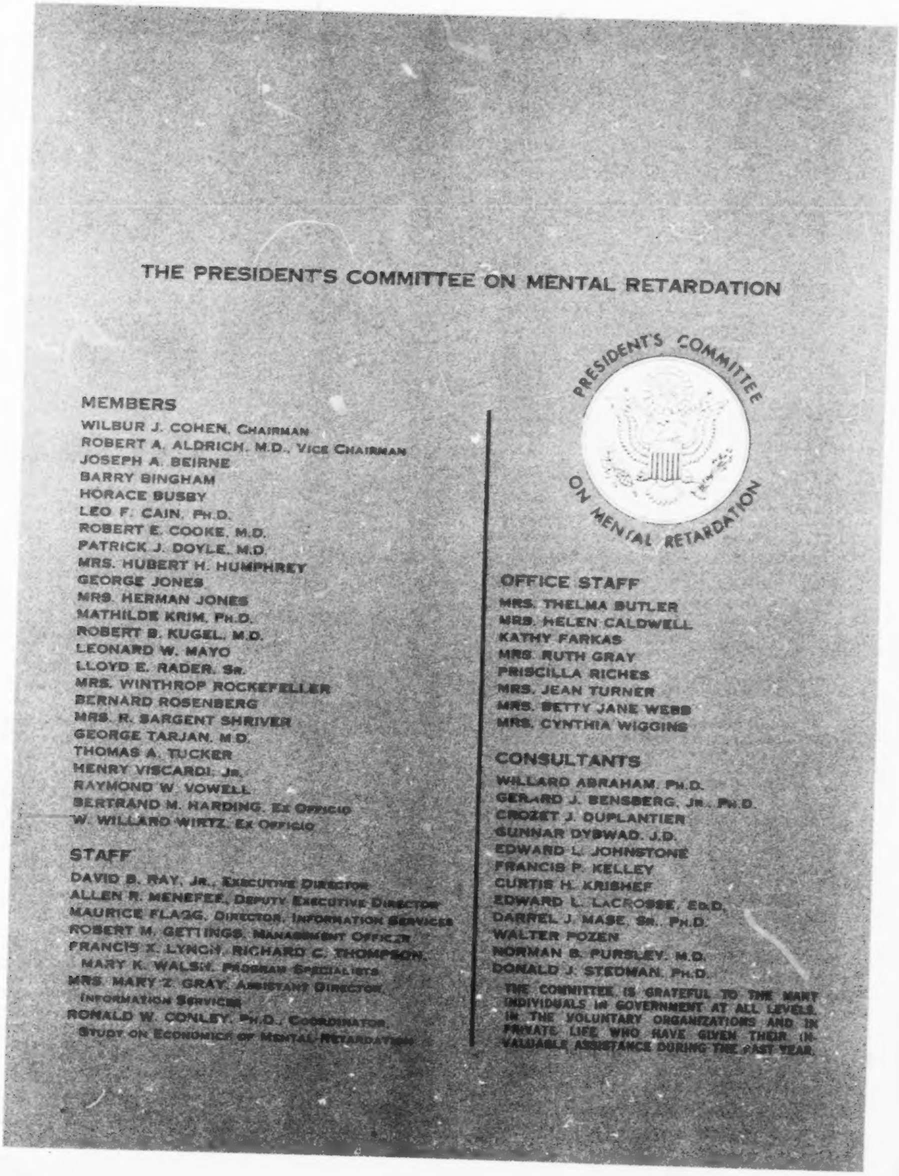
☆U.S. GOVERNMENT PRINTING OFFICE : 1968 O—310-156



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THE COMMITTEE IS GRATEFUL TO THE MANY INDIVIDUALS IN GOVERNMENT AT ALL LEVELS, IN THE VOLUNTARY ORGANIZATIONS AND IN PRIVATE LIFE WHO HAVE GIVEN THEIR INVALUABLE ASSISTANCE DURING THE PAST YEAR.

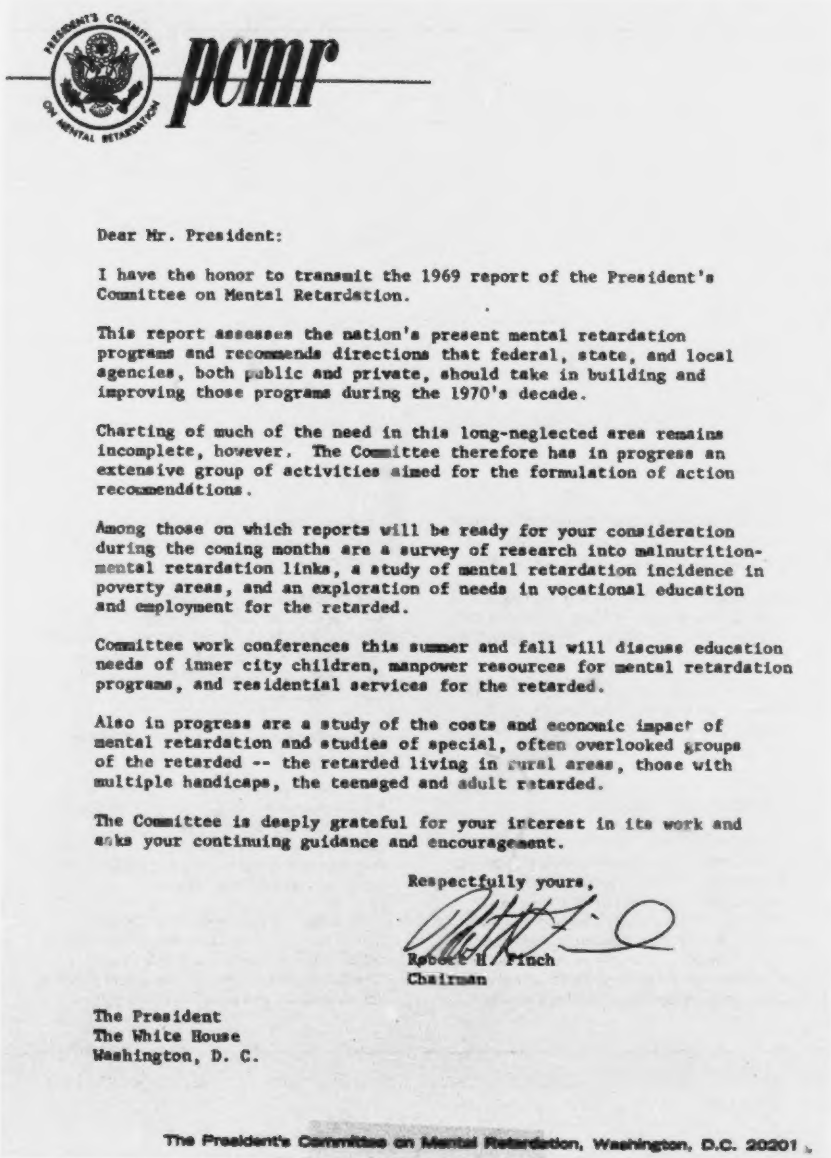
MR 69:

TOWARD PROGRESS: The Story of a Decade

A third report by the President's Committee on Mental Retardation
about developments in the national campaign to overcome mental retardation

What has to be done, has to be done by government and people together or it will not be done at all. . . . To match the magnitude of our tasks, we need the energies of our people—enlisted not only in grand enterprises, but more importantly in those small, splendid efforts that make headlines in the neighborhood newspaper. . . . With these, we can build a great cathedral of the spirit—each of us raising it one stone at a time, as he reaches out to his neighbor, helping, caring, doing.

—**President Richard M. Nixon**



pcmr

Dear Mr. President:

I have the honor to transmit the 1969 report of the President's Committee on Mental Retardation.

This report assesses the nation's present mental retardation programs and recommends directions that federal, state, and local agencies, both public and private, should take in building and improving those programs during the 1970's decade.

Charting of much of the need in this long-neglected area remains incomplete, however. The Committee therefore has in progress an extensive group of activities aimed for the formulation of action recommendations.

Among those on which reports will be ready for your consideration during the coming months are a survey of research into malnutrition-mental retardation links, a study of mental retardation incidence in poverty areas, and an exploration of needs in vocational education and employment for the retarded.

Committee work conferences this summer and fall will discuss education needs of inner city children, manpower resources for mental retardation programs, and residential services for the retarded.

Also in progress are a study of the costs and economic impact of mental retardation and studies of special, often overlooked groups of the retarded -- the retarded living in rural areas, those with multiple handicaps, the teenaged and adult retarded.

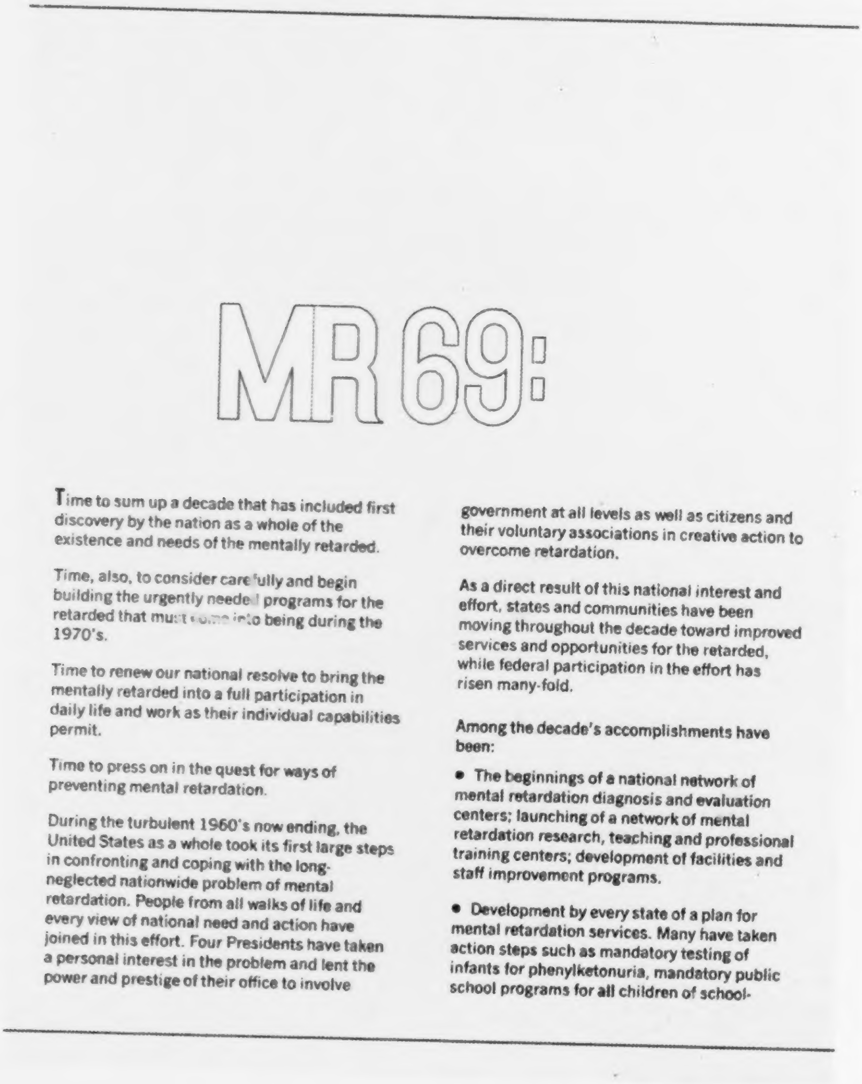
The Committee is deeply grateful for your interest in its work and asks your continuing guidance and encouragement.

Respectfully yours,

Robert H. Finch
Chairman

The President
The White House
Washington, D. C.

The President's Committee on Mental Retardation, Washington, D.C. 20201



MR 69:

Time to sum up a decade that has included first discovery by the nation as a whole of the existence and needs of the mentally retarded.

Time, also, to consider carefully and begin building the urgently needed programs for the retarded that must come into being during the 1970's.

Time to renew our national resolve to bring the mentally retarded into a full participation in daily life and work as their individual capabilities permit.

Time to press on in the quest for ways of preventing mental retardation.

During the turbulent 1960's now ending, the United States as a whole took its first large steps in confronting and coping with the long-neglected nationwide problem of mental retardation. People from all walks of life and every view of national need and action have joined in this effort. Four Presidents have taken a personal interest in the problem and lent the power and prestige of their office to involve government at all levels as well as citizens and their voluntary associations in creative action to overcome retardation.

As a direct result of this national interest and effort, states and communities have been moving throughout the decade toward improved services and opportunities for the retarded, while federal participation in the effort has risen many-fold.

Among the decade's accomplishments have been:

- The beginnings of a national network of mental retardation diagnosis and evaluation centers; launching of a network of mental retardation research, teaching and professional training centers; development of facilities and staff improvement programs.
- Development by every state of a plan for mental retardation services. Many have taken action steps such as mandatory testing of infants for phenylketonuria, mandatory public school programs for all children of school-

attendance age, vaccination of children and adults against measles.

- Increased acceptance of the retarded as trainees in vocational rehabilitation programs and a rapid growth, as a result, of employment opportunities for trained retarded workers.

- Improved relationships between the biomedical and education fields in human development programs; development of a national network of education resource and instructional materials centers for education of the handicapped.

- Major advances in public awareness of the retarded and their needs, spurred by an Advertising Council-conducted national public service advertising campaign that continued for 3½ years.

- Dramatic growth in numbers of volunteers serving the retarded; founding of the first national organization of youth serving the retarded.

- Significant growth in community mental retardation programs and in the concepts of family- and community-based activities for the retarded.

- Development and acceptance of medical procedures through which some mental retardation having biomedical causes can be predicted, diagnosed and prevented.

- Focusing of attention on the extraordinarily high incidence of retardation in poverty areas.

Dramatic and historic though these accomplishments are, however, **they are beginnings only**. They have enabled us to chart the size of the national problem of mental retardation and to favorably dispose many Americans toward action to overcome the problem. But tremendous needs and problems remain. Among them:

- The staggering problems of human underdevelopment and underperformance in the nation's poverty areas continue all but untouched.

- Most mental retardation is discovered three, four and five years too late. Retarded mental development establishes itself in earliest childhood and can be most effectively countered then. But most mild retardation (which accounts for three-fourths of the mental retardation in the nation) is identified only during the school years, if then.

- Some 5 million of the nation's estimated 6 million mentally retarded are never reached by any kind of service developed specifically to meet the needs of the retarded.

- Many of the 200,000 institutionalized mentally retarded persons continue warehoused in dehumanizing residential programs that make no serious attempt to rehabilitate residents.

- In many communities, services for the retarded are inadequate or almost nonexistent because agencies will not act, are unable to

cooperate, or are prevented from acting by policies, procedures and lack of funds that restrict their development of services.

- The American people have yet to fully accept mental retardation as a mainstream challenge that can and must be met through the application of every public and private resource that citizen concern and action can bring to bear.

These are tough problems that are deeply rooted in traditional attitudes and patterns of thinking, in unexamined traditional ways of doing things, in the piecemeal ways that we Americans take our enthusiasms and our let's-do-something-about-it resolves. They are problems that will not be overcome easily or soon. The nation's initial great thrust against mental retardation during this decade, despite important accomplishments, has scarcely touched them.

We need to rededicate ourselves to the struggle with these problems if we are to make real headway in building effective services for the retarded and preventing retardation. This rededication must take place at every level of American life — in our local governing bodies as well as in our voluntary community associations, among state legislators and officials as well as in state federations of civic and service clubs, in our national leadership both public and private, among citizens of all ages, and especially among the nation's young people, soon to constitute half of the U.S. population.

As a result of assessing the nation's situation and outlook in mental retardation, this committee has identified a group of areas in which concerted public-private measures at all levels can bring significant progress in overcoming mental retardation. These areas are:

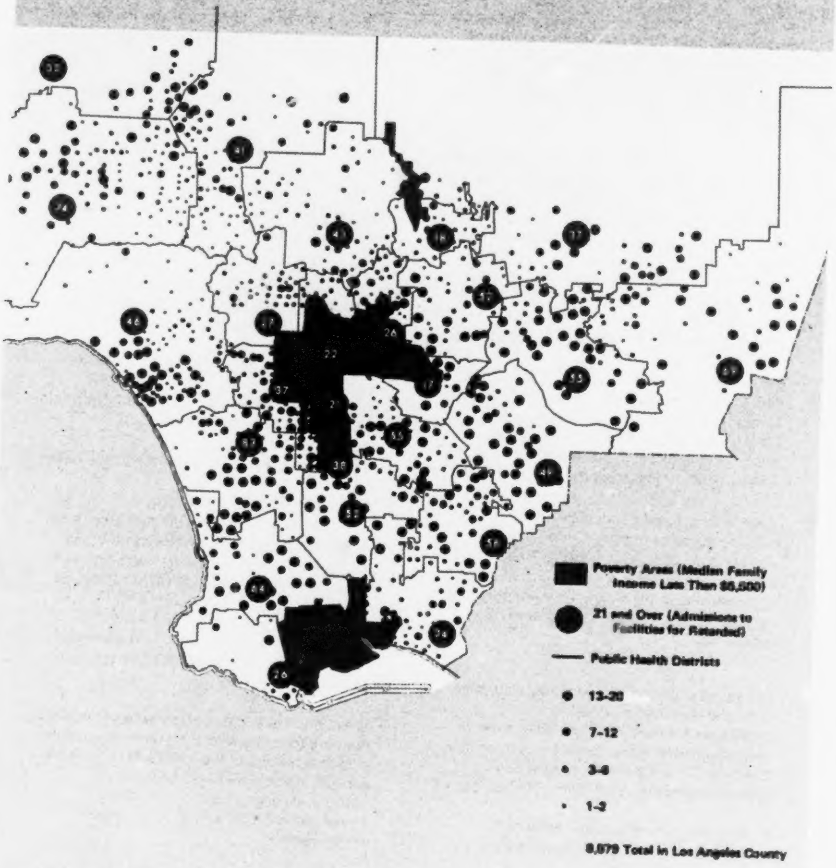
- Increasing the availability of mental retardation services, particularly in the urban and rural low income, disadvantaged neighborhoods in which some three-fourths of the nation's mental retardation is found. (Page 9)
- Development of more and better manpower recruitment and training programs for work with the retarded. (Page 12)
- Better, more imaginative use of existing resources at all levels, as well as broader realization and use of the resource that the retarded themselves represent. (Page 16)
- Development of more public-private partnerships in mental retardation programs, services and research. (Page 21)
- Continued encouragement for basic research in mental retardation and for rapid translation of research results into service program uses. (Page 25)
- Taking into account the special education, training, guidance and other needs of the mentally retarded in social and institutional planning for the future. (Page 26)

These are the areas which this report will cover.

The Committee has already made recommendations in some of these areas and reaffirms those recommendations now (see MR 67 and MR 68, the Committee's first and second reports to the President, and Page 31 of this report). Detailed reports with recommendations in other areas are in development, some scheduled for completion and release in the last half of 1969 and early 1970.

The content of this report is a general evaluation of where the national mental retardation effort stands at the end of the 1960's decade. Some aspects of that situation that stand in particularly urgent need of attention are discussed in detail, with specific actions recommended.

TRACT DISTRIBUTION OF IDENTIFIED PROFOUND AND SEVERELY MENTALLY RETARDED PERSONS IN LOS ANGELES COUNTY


26
22
37
38
34
26
Poverty Areas (Median Family Income Less Than $5,000)
21 and Over (Admissions to Facilities for Retarded)
Public Health Districts
13-20
7-12
3-6
1-2
8,079 Total in Los Angeles County

Source: A Study In Planning, the Los Angeles County Mental Retardation Services Board, October 1968, Page 4.

Mental Retardation Services Must Reach All People Who Need Them. Particularly, Ways Must Be Found To Bring These Services To People Needing Them In The Nation's Low Income, Disadvantaged Neighborhoods.

No recent finding about mental retardation has had greater impact than the discovery that retardation rates soar in urban and rural low income areas. No estimate of mental retardation incidence in such neighborhoods is less than twice the national average. One inner city count of retarded persons found one-third of the total population in a several-block area functioning at retarded achievement levels!

The facts operating to create such disproportionately high levels of retardation in poverty areas are not all known with certainty. Little doubt remains, however, that prominent among them are mother and child malnutrition, chronic disease-producing surroundings, and the harsh conditions in which countless children of poverty are reared. In such conditions, children are often deprived of the stimuli of touch, talk, shared activity and encouragement that help produce growth and learning.

The response to this disastrous situation has so far been slow, uneven and groping. There are some Head Start programs for retarded children, and a few local associations for retarded children have now joined in cooperative inner city programs for the handicapped while others are working closely with Model Cities planners.

Representatives from low income or minority neighborhoods are beginning to be welcomed on retarded children association boards and public agency advisory panels at community and state levels.

Day care for small children is outgrowing its babysitting origins and moving toward educational, recreational and social growth activities that help foster physical and mental development.

Comprehensive health care services that begin as early as possible in pregnancy and follow mother and child through the critical early childhood years are now available (although not necessarily extensively used) in a few inner city areas.

Some school systems are reexamining both regular and special instruction, seeking ways to teach that are relevant in the lives of those being taught and help each child succeed in learning to the fullest of his individual abilities.

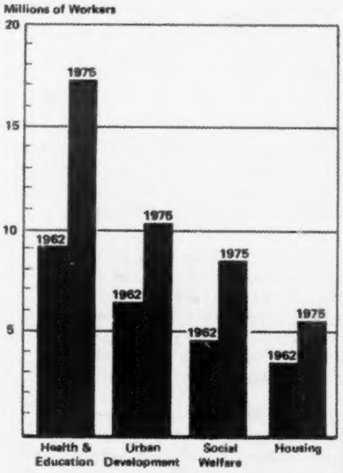
A major action response to the need is the National Association for Retarded Children-National Urban League-Family Service Association of America joint demonstration project ("Project FINE") of developing effective ways of serving the inner city retarded; this project is just getting under way in five cities.

There should be scores of such cooperative efforts joining national voluntary, civic and service organizations in action programs to help overcome child and adult-crippling handicaps in city and rural poverty areas. We call on every citizen to find out what his community service organizations are doing to help in this urgent need, to join in any effort being made, to take leadership if no effort is under way.

Most experts now agree that comprehensive health, educational and physical development programs begun in earliest childhood offer the best hope of preventing the great bulk of the physical, mental and emotional handicaps that impose such enormous cost in wasted or hobbled lives today.

We also call on state and local government leaders and planners, community developers,

INCREASED NEED FOR MANPOWER IN FOUR NATIONAL AREAS HAVING IMPLICATIONS IN MENTAL RETARDATION PROGRAMS



Projection to 1975 assumes national goals for continued improvement in American life, then depicts manpower needed to support those goals. Year 1962 is for comparison.

Source: Adapted from Manpower Report of The President, 1968; Page 306.

architects, industrialists, builders and all others who create the community environment to build cities and towns that help foster healthy human development.

The most dramatic new public initiative holding out promise in the attack on handicapping conditions is the federal government's Office of Child Development, created in April by President Richard Nixon as part of his call for a national commitment to provide all American children an opportunity for healthful and stimulating development during the first five years of life. The Officte of Child Development promises to stimulate comprehensive programs for child development, combining programs that deal with the physical, social and intellectual. In carrying out its purposes, an expansion of the Parent and Child Center program has been announced.

This Committee supports and endorses the Office of Child Development's purposes and program.

We call on public agencies and voluntary organizations at all levels in American life to give creative assistance to the Office of Child Development in realizing its purposes and programs.

As President Nixon said in announcing the Office, "Our commitment to the first five years of life will not show its full results during my administration, nor in that of my successor. But if we plant the seeds and if we respond to the knowledge we have, then a stronger and greater America will surely one day come of it."

In addition, we urge once again that the public agencies and private organizations seeking to build enduringly effective programs to overcome human handicaps in poverty areas commit themselves to:

1. Maintain their priority attention to the programs for at least a generation in order to attain the goal of significantly reducing incidence of handicaps in children.

2. Involve representatives from neighborhoods or communities served in their work and planning.

Such involvement is more than desirable; it is essential. In the final analysis, the community accomplishes only what its citizens decide must be accomplished.

Nor is it enough for the national offices of locally serving organizations, both public and private, merely to give their local units a policy permission and a blessing to move to meet local needs. Many local units, with every good will and intention, do not know how to go about organizing for effective action in neighborhoods with which they have no previous contact, do not know how to cultivate and apply resources of all kinds, do not know how to assess needs and build constructive, innovative responses to those needs.

National organizations must help their local units do these things through targeted application of practical consultation, assignment of special staff and investment of new-program seed money.

MR69

There are neglected special groups of the mentally retarded whose needs and potentials call for new study and action.

Mentally retarded teenagers often slip into limbo on completion of school programs designed for them. Few communities have either social interest or vocational preparation programs to capture and hold these young people.

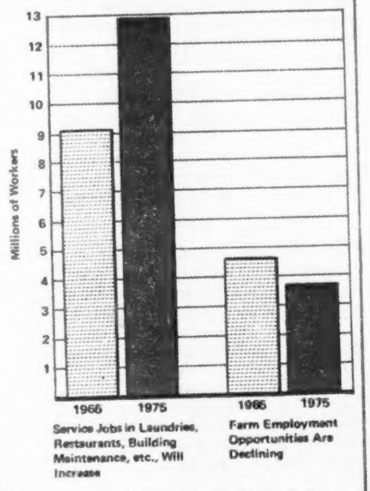
We recommend that city and county governments, in cooperation with voluntary groups interested in the retarded, move to remedy such neglect.

In every community and in every public institution for the retarded, there are retarded adults capable of living and working independently. In addition, retarded persons being trained for independent community living need a base from which to launch into the community.

These purposes and possibilities can be admirably served together through group homes —private residences in which a small number of adult retarded persons live with an individual or couple employed as "house parents." Such residences are already in successful operation in several states.

We urge their development in every state as combined residences and sources of counseling and guidance in daily living problems for the adult retarded living in the community.

CHANGING PATTERNS OF OCCUPATIONS WILL ALLOW MORE MENTALLY RETARDED TO BE EMPLOYED IN SERVICE JOBS



Source: Adapted from Manpower Report of the President, U.S. Department of Labor, March 1969.

Improved Manpower Recruitment And Training Programs For Work With The Mentally Retarded Must Be Developed.

The gap between needed and available services in mental retardation programs grows wider daily. A major cause of this situation is lack of hands to provide the services. Why this lack? Programs are often so inadequately funded that they cannot attract and keep either professional or support staff. And even available workers are poorly deployed in many cases.

Shortages of professional skills, serious though they are, are not as great as those of supportive workers—attendants, aides and other specialists' assistants. Here the shortages can have disastrous effects. Supportive workers are more often and regularly in contact with the retarded than any other workers in residential programs and make a crucial contribution in community programs.

The kind of day-to-day life a retarded person lives often depends directly on the number and quality of supportive workers. The great shortage of supportive workers in mental retardation programs, this Committee believes, is the key problem in the retardation program manpower field. It must be solved.

The public and private agencies that employ supportive workers in their programs for the retarded should undertake a general upgrading of those personnel and their positions by whatever practicable means they can devise.

We recognize that such an upgrading cannot be carried out overnight. Nor can it be carried out in a vacuum in which the managers of programs for the retarded are left to work out new procedures as best they can.

In mental retardation programs operated by the states, the state itself—its legislators and officials—must move to change laws and regulations that have fastened archaic personnel

practices on public programs for the handicapped and needy.

Citizens themselves should demand and be prepared to support upgradings in status and salaries for supportive workers in private agency programs for the handicapped.

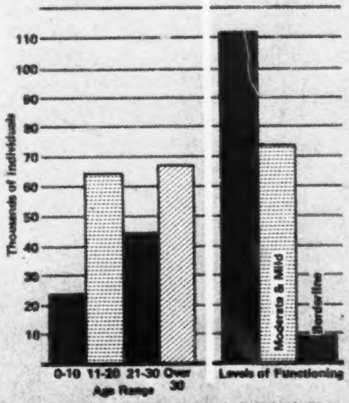
Citizen groups, colleges and universities and professional organizations can make invaluable contributions to the success of this effort. The many civic and service organizations that have long prided themselves on support of scholarships for students training as professional specialists might now also consider establishing scholarships for the training of assistants to such specialists.

Colleges and universities should establish practical, work-related courses leading to professional certification for assistants in social and institutional service programs. Community colleges and 2-year colleges, especially, have an important contribution to make in this area through programs of training that are geared directly to community needs and on-job experience.

And professional organizations, **in the interest of their own members' greater professional effectiveness,** should analyze the application of work and skills in social service settings with a view to redefining the roles and functions of specialists and their trained assistants. Aim of this analysis: to obtain maximum spread of available people and skills to meet needs.

These measures will bring a new deployment of staff resources in which all participants will be personally and professionally effective, competent and recognized. Such a revamped system, we believe, will **reduce** the proportion of public and private monies needed for mental retardation program personnel resources.

The major responsibility for making this reform belongs to the states and to the private, voluntary organizations that serve the retarded in the community. But the federal government, too, should take a leading part.



SPECIAL GROUPS OF RETARDED NEED SERVICE

A survey of 168 residential care facilities indicates that the resident population of 201,000 includes high percentages of adolescents and persons over 30 who are profoundly and severely retarded. Services need to be planned for this population.

Source: Adapted from American Association on Mental Deficiency, Division of Special Studies, Institutional Evaluation Project, 1969.

Cooperatively, through the Departments of Labor and Health, Education, and Welfare, the federal government should furnish a counseling service through which field teams of expert community and institution service organizers help states and private organizations plan and carry out supportive staff upgrading and over-all improvements in staff deployment in programs for the retarded and other handicapped persons.

Better deployment of supportive staff in programs for the retarded will help reduce present shortages of professional specialists. But preparation of such specialists to meet tomorrow's mental retardation services needs must continue.

The existing federal grant, scholarship and work training programs for specialists in work with the handicapped should be continued and expanded, with greater tuition assistance being made available for college undergraduates.

In addition, we now need to make long-term, federally-supported utilization of experience from the immensely successful, low-cost programs through which disadvantaged youth, college students and senior citizens have been working as aides in programs for the retarded.

Among these have been the Student Work Experience and Training (SWEAT), Volunteers in Service to America (VISTA) and Foster Grandparent programs.

Finally, the widespread and fast-growing interest of youth and college students in volunteer service with the retarded should be put to meaningful work by every agency and group concerned with the retarded. Their interest is already being expressed in scores of voluntary organization activities with the handicapped. It is exemplified in the growth of the NARC-Youth membership to 97,000 in 2 years. From the ranks of these teenagers and young adults will come many of the coming decade's program leaders, staff, volunteers and community supporters.

dog

Fuller, More Imaginative Use Of Resources—Including The Resource Which The Retarded Themselves Represent—Is Needed At All Levels.

The belief that large infusions of federal money alone can produce better programs and facilities is as mistaken in the mental retardation field as in any other. If there is to be long-term healthy growth and effectiveness in mental retardation programs and facilities, state and local governments—with citizen, corporate, foundation and private agency participation—must furnish the majority of their support.

No less mistaken, however, is the belief among some federal government planners that a federal fund cut-off or reduction will bring state or local government assumption [illegible] co[illegible] the affected program. Such [illegible] sounds the progra[illegible]

We urge, the[illegible] mental retar[illegible] demonstra[illegible] (includin[illegible] continu[illegible] and re[illegible] withi[illegible]

We a[illegible] facili[illegible] appr[illegible] of Co[illegible] for a [illegible] retard[illegible] be reali[illegible]

At the sa[illegible] governme[illegible] services a[illegible] program o[illegible] jurisdiction[illegible]

MENTALLY RETARDED ADULTS

JOB TITLE	NUMBER
Animal Caretaker	5
Bindery Worker	5
Building Maintenance Wkr.	114
Buoy Maintenance Helper	2
Card Punch Operator	51
Carpenter	1
Carpenter Helper	5
Cartographic Aide	3
Charman	2
Clerk	629
Clerk, File	158
Clerk (Money Counter)	3
Clerk (Numbering)	2
Clerk-Receptioni[illegible]	1
Clerk-Typist	89
Control Cl[illegible]	6
Cook	1
Curren[illegible]	1
Dishw[illegible]	5
Elevat[illegible]	11
[illegible]	[illegible]
[illegible]	[illegible]
F[illegible]	219
F[illegible]	14
[illegible]	3
[illegible] H[illegible]	[illegible]
[illegible]	[illegible]
[illegible] Wo[illegible]	[illegible]
[illegible]	[illegible]
[illegible]	[illegible]
[illegible]	[illegible]
[illegible]	[illegible]
[illegible]	4

EMPLOYED BY THE FEDERAL GOVERNMENT

JOB TITLE	NUMBER
Laundry Worker	273
Library Assistant	7
Mail Clerk	170
Mail Clk. (Motor Veh. Opr.)	1
Mail and File Clerk	27
Mail Handler	186
Medical Technician	8
Messenger	296
Mess Attendant	445
Nursery Worker	3
Office Draftsman	2
Office Machine Operator	164
Paint Worker	2
Photocopy Operator	8
Photographic Processing Aide	7
Physical Science Aide	5
Porter	18
Press Cleaner	9
Presser (Flatwork)	15
Printing Plant Worker	22
Publications Supply Clerk	17
Radio Repairer Helper	1
Sales Store Worker	16
Small Arms Repairer Helper	6
Stock Clerk	77
Substitute Mail Handler	734
Supply Clerk	23
Telephone Operator	1
Vehicle Maintenance Wkr.	10
Ward Attendant	13
Warehouseman	26
Washman	15
Washman Helper	17
TOTAL:	5784

The U.S. Civil Service Commission has written agreements with 42 federal departments and agencies to employ the mentally retarded in accordance with federal personnel practices. In mid-1969, the government employed 5,784 mentally retarded persons in 65 job titles.

Source: Adapted from Reports by the U.S. Civil Service Commission and the President's Committee on Employment of the Handicapped, 1969.

The essence of stimulating healthy development and change (where needed) in programs for the retarded throughout the nation lies in persuading local and state authorities such as county commissioners and state legislators that they must give serious attention to how effectively, in terms of results in people's lives, are spent the huge sums—now three-quarters of a billion dollars a year—that they appropriate for mental retardation programs.

Unless mental retardation program leaders and interested citizens throughout the nation accept this challenge and bring retardation needs into priority focus in citizen thinking and governmental action **in their own states and communities,** the national effort to combat mental retardation and improve life and prospects for the retarded will be essentially rootless.

MR 69:

Perhaps the most overlooked resource of all in the mental retardation field is . . . the retarded themselves.

Some three-quarters of this nation's retarded people could become self-supporting if given the right kind of training early enough. Another 10 to 15 percent could become partially self-supporting.

Are we capturing this potential and putting it to work? Some of it, yes. Most of it, no. Hundreds of thousands of retarded persons who could be trained and educated to useful work and life in American society are being wasted. Why?

One reason is that the nation's public school systems have not, in the main, accepted responsibility to educate all children.

A few states now require education programs for all children of school attendance age. Most, however, effectively exclude many handicapped children by offering few or no programs for them, while tens of thousands of retarded children, too mildly affected to be assigned to traditional classes for the educable or trainable retarded, stumble as best they can through regular classes. These drop out of school as soon as they can, often to fall into the marginal-subsistence spawning grounds of chronic welfare, health and social problems.

Another reason (closely related to the preceding one) that many retarded people arrive at adulthood unprepared for job or daily living is that many educators look at what a retarded child isn't, not at what he is.

The resulting curricula, developed with the retarded child's deficiencies rather than his abilities in mind, merely simplify and water down the course of instruction given normal children. Such programs require achievement in the academic areas where the retarded child is weaker and give little or no encouragement to the pragmatic skill areas in which he can accomplish something.

Moreover—compounding the error to an incalculable degree—the school program for a retarded young person often takes no account of his age, offering the same content and approach when he is 16 as when he was 6.

Most retarded young people need training that develops skills and attitudes for daily work and living.

For most, this should be a program that looks to the pupil's eventual independent living in the community. For some, it should point toward sheltered work and living arrangements.

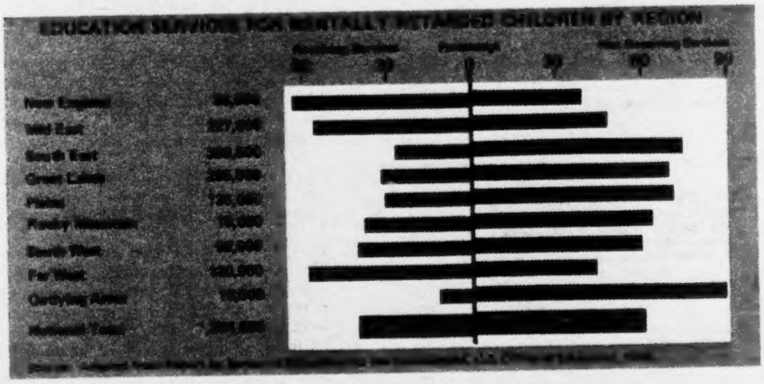
It should in any case be a realistic curriculum that readies individuals to meet the actual demands of daily living and to work in jobs that actually exist in the community.

Business, industry and labor could play a much more significant role in this effort than they presently do.

Among the needed measures requiring business and labor expertise are:

- Cooperative school-business programs to develop and assure training and work experience opportunities for mentally retarded students in special and vocational education classes.

- More direct, cooperative relationships between industry and vocational rehabilitation programs, so that there is a minimum of time loss between completion of training and job placement of handicapped workers. (Many



trained retarded workers are lost to the work force during this period.)

- Special attention, in job training programs for the core city disadvantaged, to the mentally retarded job candidate. The National Alliance of Businessmen should be asked to develop programs and approaches that could make a significant contribution in this connection.

- Application of business and labor techniques and expertise to job redesign, job training and retraining, and the operation of special work facilities for the severely handicapped.

In particular reference to the last, occupational centers for the handicapped are often in desperate need of contract, materials and other support coordination. Industry, local government and private agencies should work together on these problems to develop coordinated procedures that assure maximum cost-effectiveness of center operations.

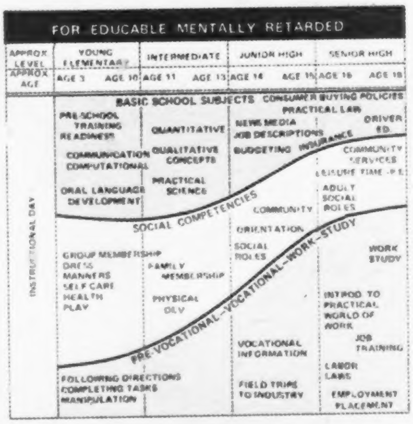
- Promotion of trained retarded workers' employability and job success should be intensified to reach the broadest possible spectrum of business and industry.

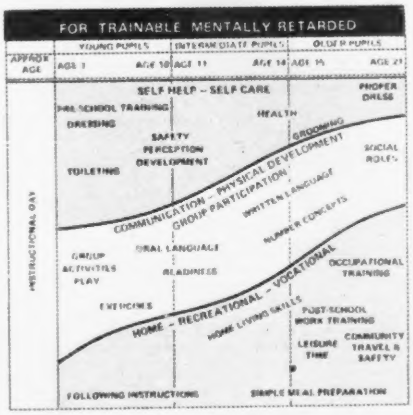
More industry-wide training and employment projects—of the kind that the National Association for Retarded Children, President's Committee on Employment of the Handicapped and the Department of Labor have been so ably promoting—should be stimulated and carried out. Industry should develop in-plant centers for handicapped workers and integrate the work of these centers into their regular production lines.

Finally, an on-going counseling service should be available to the retarded who are on their own in the community. (See also Page 11.)

Today's complex challenges of living and working pose puzzling enough dilemmas to people with normal intelligence and adaptive abilities. The retarded need special, expert guidance in coping with problems. The commuity should furnish that guidance.

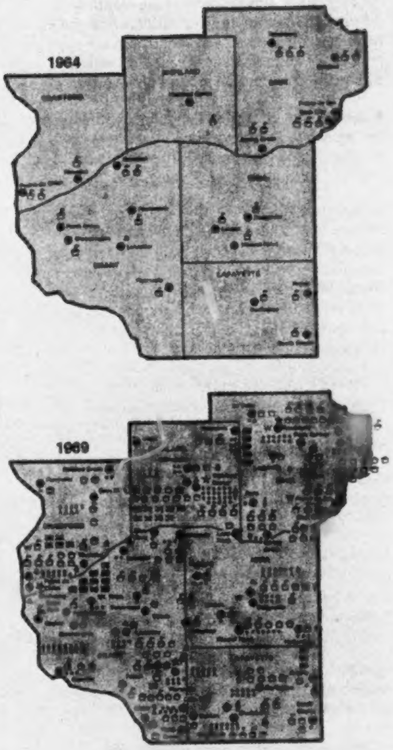
GENERAL CURRICULUM EMPHASIS


FOR EDUCABLE MENTALLY RETARDED
APPROX LEVEL
YOUNG ELEMENTARY
INTERMEDIATE
JUNIOR HIGH
SENIOR HIGH
APPROX AGE
AGE 3
AGE 10
AGE 11
AGE 13
AGE 14
AGE 15
AGE 16
AGE 18
INSTRUCTIONAL DAY
BASIC SCHOOL SUBJECTS
CONSUMER BUYING POLICIES
PRACTICAL LAW
PRE-SCHOOL TRAINING READINESS
QUANTITATIVE
NEWS MEDIA
JOB DESCRIPTIONS
DRIVER ED.
BUDGETING
INSURANCE
COMMUNICATION
COMPUTATIONAL
QUALITATIVE CONCEPTS
COMMUNITY SERVICES
LEISURE TIME - P.E.
ORAL LANGUAGE DEVELOPMENT
PRACTICAL SCIENCE
ADULT SOCIAL ROLES
SOCIAL COMPETENCIES
COMMUNITY
ORIENTATION
SOCIAL ROLES
WORK STUDY
GROUP MEMBERSHIP
DRESS
MANNERS
SELF CARE
HEALTH
PLAY
FAMILY MEMBERSHIP
PHYSICAL DEV
INTROD. TO PRACTICAL WORLD OF WORK
PRE-VOCATIONAL-VOCATIONAL-WORK-STUDY
VOCATIONAL INFORMATION
JOB TRAINING
LABOR LAWS
FOLLOWING DIRECTIONS
COMPLETING TASKS
MANIPULATION
FIELD TRIPS TO INDUSTRY
EMPLOYMENT PLACEMENT


FOR TRAINABLE MENTALLY RETARDED
YOUNG PUPILS
INTERMEDIATE PUPILS
OLDER PUPILS
APPROX AGE
AGE 3
AGE 10
AGE 11
AGE 14
AGE 15
AGE 21
INSTRUCTIONAL DAY
SELF HELP – SELF CARE
PROPER DRESS
PRE-SCHOOL TRAINING
HEALTH
DRESSING
GROOMING
SAFETY PERCEPTION DEVELOPMENT
SOCIAL ROLES
TOILETING
COMMUNICATION – PHYSICAL DEVELOPMENT
GROUP PARTICIPATION
WRITTEN LANGUAGE
NUMBER CONCEPTS
ORAL LANGUAGE
READINESS
GROUP ACTIVITIES PLAY
OCCUPATIONAL TRAINING
EXERCISES
HOME – RECREATIONAL – VOCATIONAL
HOME LIVING SKILLS
POST-SCHOOL WORK TRAINING
LEISURE TIME
COMMUNITY TRAVEL & SAFETY
FOLLOWING INSTRUCTIONS
SIMPLE MEAL PREPARATION

Source: "Study of Curriculum Planning," J. Wayne Campbell, Curriculum Consultant, California State Department of Education. Approved by California Board of Education 1968

GROWTH OF SERVICES FOR THE RETARDED IN SOUTHWESTERN WISCONSIN



- ♁ Special Education Classes
- ▲ Associations for Retarded Children
- w Work-Study Program
- ● Youth ARC
- ★ Day Care Center
- ◆ Fixed Point of Referral
- ○ Children Seen by Home Training Specialist
- • Children Examined by Traveling Diagnostic Team
- ♦ Sheltered Workshop
- ^ Southwest Badger Camp
- ≗ Wisconsin Badger Camp
- ! Children Given Psychological Testing for Admission to Special Education Classes (one figure represents 10 children)
- ● Temporary Care Home
- ▮ Adult Activity Program
- ≡ Community Placement Work

Source: Adapted from State of Wisconsin Study on Semi-Rural Community Growth in Services for the Mentally Retarded, 1968, 1969.

More Public-Private Partnerships In Mental Retardation Program Planning, Services And Research Should Be Developed.

One such partnership, a PCMR-proposed national mental retardation information and resource system, is now moving toward initial build-up. When this system is in operation, probably as a federal government-data systems corporation partnership operating under the direction of an independent board representing both public and private agency interests in the mental retardation field, it will bring together and store research and program information for quick retrieval nationwide.

Other such partnerships include the Project FINE mentioned earlier, which is partially funded by a Department of Health, Education, and Welfare grant, and the National Association for Retarded Children-Department of Labor On-the-Job Training Project.

Growth of public-private partnerships—many of them informal cooperative arrangements—has been particularly noticeable at the grassroots community level, where the crunch of small budgets and large need for services is most urgently felt.

But these fragmentary efforts are only a beginning to the partnership effort needed to help join public agency, voluntary organization and business-labor resources in a concerted application to meeting mental retardation needs. Many of the measures recommended earlier in this report and in previous reports could and should be developed through such joint action.

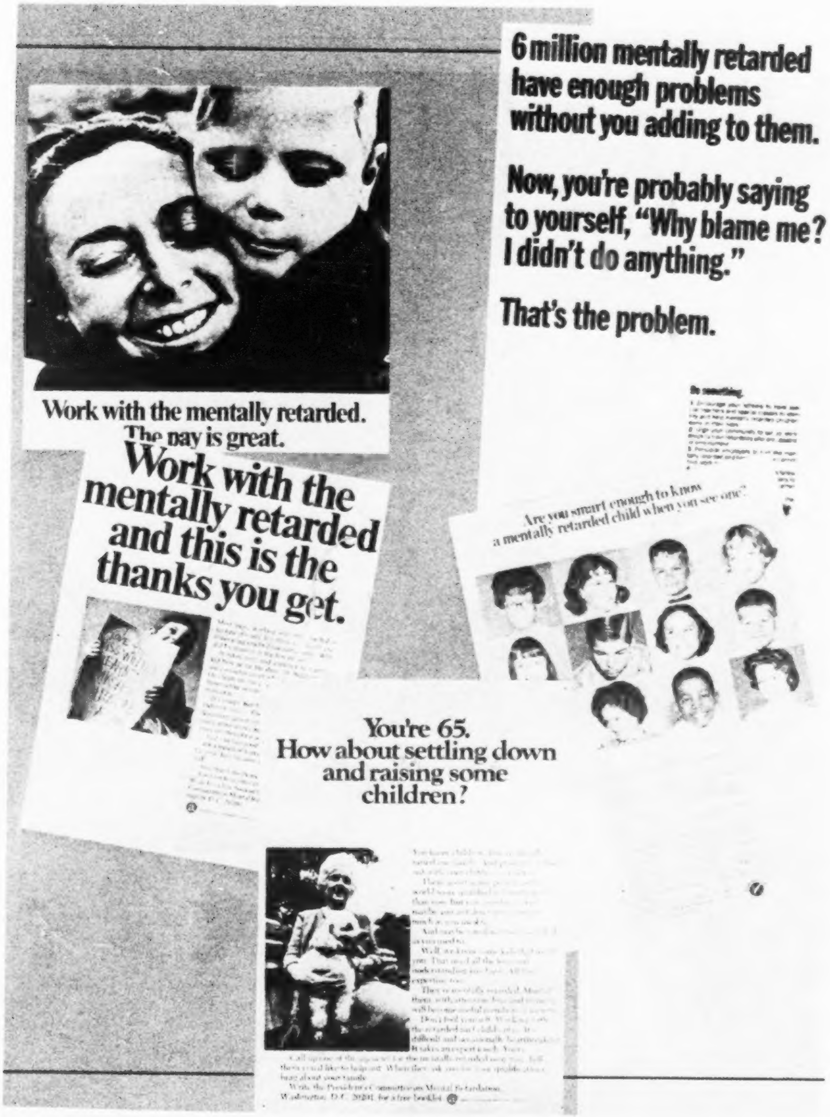
Among them:

- Comprehensive health and child development centers in poverty neighborhoods.
- Vocational and job education, training and employment programs for the retarded and other handicapped as well as job analysis and redesign to better fit retarded workers' skills and capabilities to work norms and needs, in both service and manufacturing industries.
- Establishment and operation of developmental training facilities for the retarded living in rural areas.
- Government-foundation partnerships formed to develop and carry out innovative, demonstration and special-need programs in the mental retardation field. Such partnerships might also absorb some of the cut when federal funding of local-based mental retardation programs is reduced before the community and its agencies are able to assume full program support.
- Development and cooperation of high quality residential care facilities that will permit parents or guardians of retarded individuals a free choice among varying program options. Such a choice is available today only to the affluent. In addition, states should enter public-private partnerships for the development and operation of community group homes for the retarded.
- Continuing operation of a national mental retardation public information and education campaign. An initial partnership in this area

was conducted through the Advertising Council by the President's Committee on Mental Retardation, the Department of Health, Education, and Welfare, The Joseph P. Kennedy, Jr., Foundation, and the National Association for Retarded Children.

Press, radio and television media made space and time contributions worth some $40 million during the 3½-year period of this campaign to build awareness and understanding of the retarded.

But the work is just begun. The public is now beginning to be aware of the retarded and their needs, and many have committed themselves to help in service and prevention activities. Such commitment, however, has been made by too few as yet. A genuine broad acceptance of retardation as a major problem of our society and of the retarded as fellow human beings having individuality, dignity and a personal stake in daily life and work is, regrettably, still far off.



6 million mentally retarded have enough problems without you adding to them.

Now, you're probably saying to yourself, "Why blame me? I didn't do anything."

That's the problem.

Work with the mentally retarded. The pay is great.

Work with the mentally retarded and this is the thanks you get.

Are you smart enough to know a mentally retarded child when you see one?

You're 65. How about settling down and raising some children?

ssroom
oratory

Basic Research In Mental Retardation And Rapid Translation Of Research Results Into Service Program Uses Need Continued Encouragement.

Man's curiosity has led him to explore the remotest crannies of his planet, go to the sea bottom at its deepest, conquer the highest mountain peaks, fly out from his earth and contemplate voyages to the stars.

But there is no greater wonder to be met in these voyages than the creature who makes them: Man himself.

And of him we know very little. Almost any of us knows more about astrophysics than about how the human creature grows and learns.

Mental retardation is a result of imperfect development in the human growing and learning processes. Research into its causes, effects, prevention and treatment can reveal much to us about normal development as well. Thus, mental retardation research has implications far beyond the condition itself.

Human development research in recent years has made findings of incredible portent. We can now see the tiny "tape" of matter, called DNA, by which human life in all its individual variants is passed from generation to generation. We can already make out some of the codings on that "tape" and see how variations on the tape are forerunners of differences—some of them "normal" variations such as eye color, some of them developmental anomalies—in individual human beings.

As we become more expert at reading the codings, we discover that we know enough in some cases to predict possibilities and degrees of developmental problem risk. Thus, for example, from our present knowledge of some human chromosome-child development abnormality relationships, we can discover some of the couples who may produce a retarded child.

At the same time, major strides have been made in educational, behavioral and social science research. Fully as important as the biomedical research reported above, studies in behavior and the social sciences have found that human behavior can be modified in constructive ways, that the time of most rapid human growth and development is in earliest childhood, and that the "programming" from which the individual operates throughout his life in making his choices and decisions is largely set before his formal school learning process begins.

The basic research that has produced these historic findings continues critically needed, as does the research and experimentation that makes the outcomes of such findings conveniently, economically available to every American needing them. We urge that human development research be included in the first rank of the nation's action priorities and that broad-based public and private support from the health, education, social service, behavior and related fields be given to such research.

In this connection, we applaud President Nixon's action, in early May, directing the Secretary of Health, Education, and Welfare to initiate detailed research into the relationship between malnutrition and mental retardation.

Equally important for the mentally retarded as well as all other Americans is the need for more and better information about how we learn. Research in this vital area is being carried on in often unrelated small fragments throughout the nation's 20,000 school districts and 5,000 institutions of higher education. Much of this research is so narrow-targeted, so esoteric in interest and so locked into a single professional discipline as to have little general use or value.

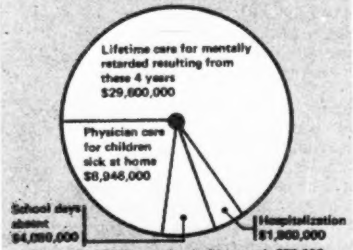
To stimulate and coordinate research into the basic human learning processes, therefore, we urge action now on the establishment of a

national learning institute or foundation. This foundation would particularly promote investigations of human learning processes and potential that join a number of disciplines. The foundation should be a public-private partnership organized and funded in much the same way as the National Science Foundation.

An aspect of research of critical importance in today's fast-changing and explosively growing communities is the study of service delivery needs and development of workable grassroots systems in response to those needs. Research breakthroughs in human development and learning will be useless unless the findings can be translated into services that reach and aid people in their homes, schools and work.

We recommend, therefore, that public agencies and private organizations having programs related to human development and learning problems such as mental retardation earmark a steady portion of their budgets to the cooperative evaluation and application of new information affecting their programs.

ONE MILLION MEASLES CASES IN NEXT 4 YEARS* COULD COST U.S. ECONOMY $45,000,000



*Based on 1966 measles incidence of 225,000 cases nationwide, projected. Preliminary compilations of 1968 data find the rate holding steady or increasing slightly.

Source: Adapted from data surveyed by Pitman and Moore Division of the Dow Chemical Company. Projections are based on a Rhode Island study in 1967.

The Special Needs Of The Mentally Retarded Should Be Taken Into Account In Social And Residential Care Planning For The Coming Decades

Until major mental retardation preventive measures have been established and are producing results, we must expect and accept the fact of a large number of mentally retarded individuals in the U.S. population. The best estimates place that number presently at around 6 million individuals. The total, of course, will grow with the population.

We must plan for the lives and careers of these retarded in tomorrow's communities, schools, working places, leisure-time programs and residential facilities.

And we must make as great as possible integration of the retarded into normal community living and working patterns the objective of that planning.

In the community of the future there should be no such thing as a separate population of mentally retarded people for whom there are special group programs.

The total integration of the retarded into normal community living, working and service patterns is a long-range objective. But now is the time to begin working toward it by creating the channels through which both the regular and special services needed by the retarded can be given in a unified group of public and private programs working to help all handicapped people realize their full potential.

One part of meeting the challenge of bringing the retarded humanely and effectively into the community of human concern and endeavor must be the final eradication of the system that crowds large numbers of retarded people together in warehouse-like living conditions. No matter how many individuals may be involved—whether 5, 50 or 5,000—residential and other programs for the retarded that are group custodial in nature destroy the potential for growth and development among those confined in them. Such programs are a standing reproach to our national professions of concern for the individual.

Every state that has large, mass custody programs for the retarded should move vigorously to develop quality programs that are aimed at habilitation of retarded individuals for fullest possible participation in community living and work.

MR 69:

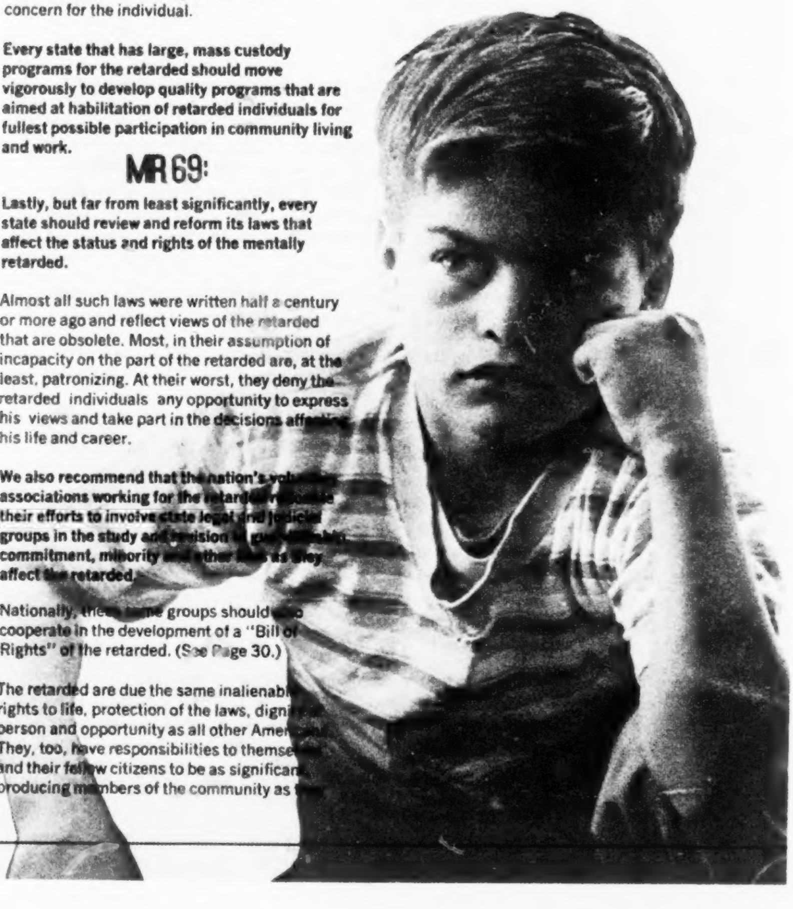
Lastly, but far from least significantly, every state should review and reform its laws that affect the status and rights of the mentally retarded.

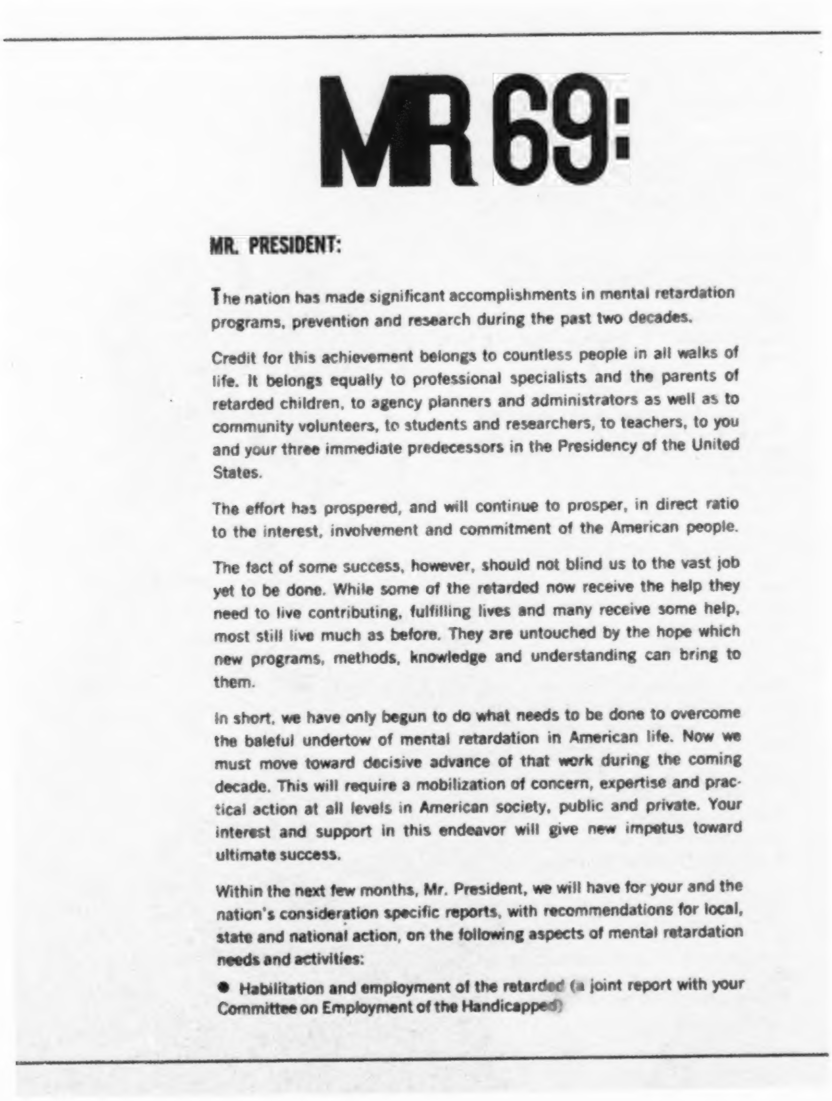
Almost all such laws were written half a century or more ago and reflect views of the retarded that are obsolete. Most, in their assumption of incapacity on the part of the retarded are, at the least, patronizing. At their worst, they deny the retarded individuals any opportunity to express his views and take part in the decisions affecting his life and career.

We also recommend that the nation's voluntary associations working for the retarded redouble their efforts to involve state legal and judicial groups in the study and revision of guardianship, commitment, minority and other laws as they affect the retarded.

Nationally, these same groups should also cooperate in the development of a "Bill of Rights" of the retarded. (See Page 30.)

The retarded are due the same inalienable rights to life, protection of the laws, dignity of person and opportunity as all other Americans. They, too, have responsibilities to themselves and their fellow citizens to be as significantly producing members of the community as they can. These basic rights and responsibilities should be expressed in state laws affecting the retarded. Only a few states, however, have taken steps in this direction.





MR 69:

MR. PRESIDENT:

The nation has made significant accomplishments in mental retardation programs, prevention and research during the past two decades.

Credit for this achievement belongs to countless people in all walks of life. It belongs equally to professional specialists and the parents of retarded children, to agency planners and administrators as well as to community volunteers, to students and researchers, to teachers, to you and your three immediate predecessors in the Presidency of the United States.

The effort has prospered, and will continue to prosper, in direct ratio to the interest, involvement and commitment of the American people.

The fact of some success, however, should not blind us to the vast job yet to be done. While some of the retarded now receive the help they need to live contributing, fulfilling lives and many receive some help, most still live much as before. They are untouched by the hope which new programs, methods, knowledge and understanding can bring to them.

In short, we have only begun to do what needs to be done to overcome the baleful undertow of mental retardation in American life. Now we must move toward decisive advance of that work during the coming decade. This will require a mobilization of concern, expertise and practical action at all levels in American society, public and private. Your interest and support in this endeavor will give new impetus toward ultimate success.

Within the next few months, Mr. President, we will have for your and the nation's consideration specific reports, with recommendations for local, state and national action, on the following aspects of mental retardation needs and activities:

- Habilitation and employment of the retarded (a joint report with your Committee on Employment of the Handicapped)

- The relationships between poverty and mental retardation.
- Education programs for the retarded, including suggested curricula.
- Research completed and under way into the relationship between malnutrition and mental retardation.
- Lead poisoning as a cause of mental retardation.

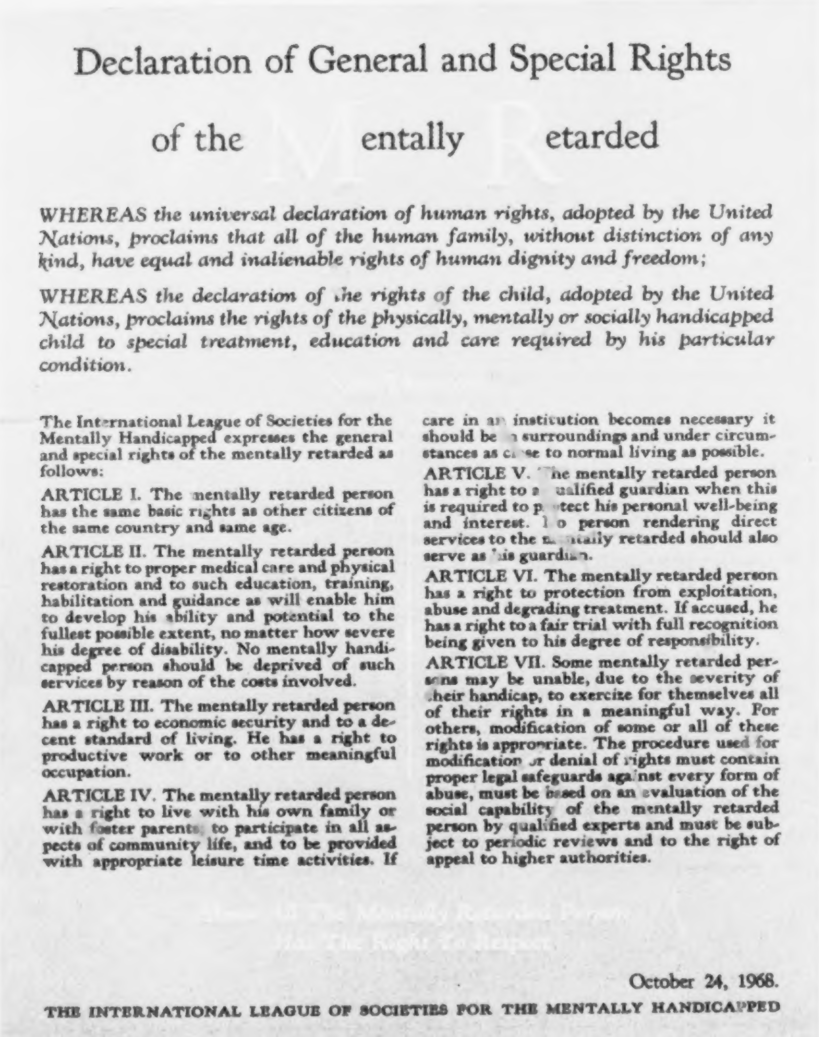
We shall be holding work conferences bringing together program experts, community planners, parents, educators and scientific authorities to explore and make recommendations on:

- Problems of education in the inner city, with special reference to the needs for special education programs for handicapped learners.
- The introduction and implementation of change in residential services for the mentally retarded.
- Recruitment, training and deployment of manpower resources to meet mental retardation service needs.

Also in preparation are reports, with recommendations, on:

- The economic costs and impact of mental retardation in the national economy.
- Nationwide needs, problems and change patterns in special education for the retarded as well as other handicapped.
- Special needs and problems of the adult mentally retarded.
- Special needs and problems of the retarded who live in rural areas.

We ask your aid, Mr. President, in endorsing the release of this report to the public and in urging action at all levels for a continuing, effective national attack on the problem of mental retardation.



Declaration of General and Special Rights of the Mentally Retarded

WHEREAS the universal declaration of human rights, adopted by the United Nations, proclaims that all of the human family, without distinction of any kind, have equal and inalienable rights of human dignity and freedom;

WHEREAS the declaration of the rights of the child, adopted by the United Nations, proclaims the rights of the physically, mentally or socially handicapped child to special treatment, education and care required by his particular condition.

The International League of Societies for the Mentally Handicapped expresses the general and special rights of the mentally retarded as follows:

ARTICLE I. The mentally retarded person has the same basic rights as other citizens of the same country and same age.

ARTICLE II. The mentally retarded person has a right to proper medical care and physical restoration and to such education, training, habilitation and guidance as will enable him to develop his ability and potential to the fullest possible extent, no matter how severe his degree of disability. No mentally handicapped person should be deprived of such services by reason of the costs involved.

ARTICLE III. The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to productive work or to other meaningful occupation.

ARTICLE IV. The mentally retarded person has a right to live with his own family or with foster parents, to participate in all aspects of community life, and to be provided with appropriate leisure time activities. If care in an institution becomes necessary it should be in surroundings and under circumstances as close to normal living as possible.

ARTICLE V. The mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interest. No person rendering direct services to the mentally retarded should also serve as his guardian.

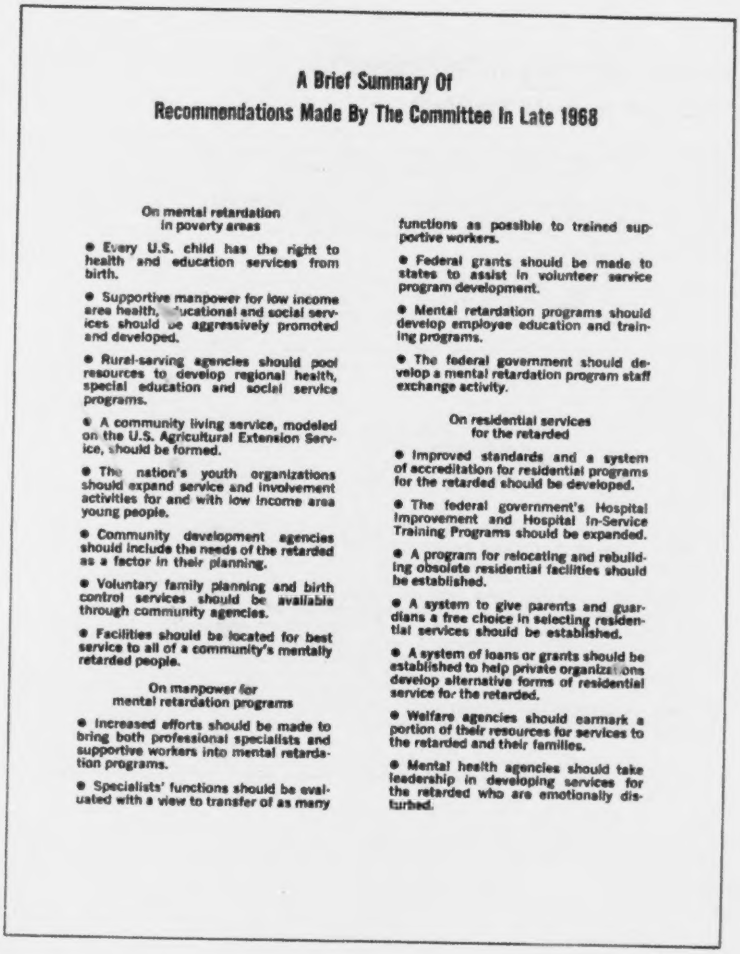
ARTICLE VI. The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If accused, he has a right to a fair trial with full recognition being given to his degree of responsibility.

ARTICLE VII. Some mentally retarded persons may be unable, due to the severity of their handicap, to exercize for themselves all of their rights in a meaningful way. For others, modification of some or all of these rights is appropriate. The procedure used for modification or denial of rights must contain proper legal safeguards against every form of abuse, must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic reviews and to the right of appeal to higher authorities.

Above All The Mentally Retarded Person
Has The Right To Respect

October 24, 1968.

THE INTERNATIONAL LEAGUE OF SOCIETIES FOR THE MENTALLY HANDICAPPED



A Brief Summary Of Recommendations Made By The Committee In Late 1968

On mental retardation in poverty areas

- Every U.S. child has the right to health and education services from birth.
- Supportive manpower for low income area health, educational and social services should be aggressively promoted and developed.
- Rural-serving agencies should pool resources to develop regional health, special education and social service programs.
- A community living service, modeled on the U.S. Agricultural Extension Service, should be formed.
- The nation's youth organizations should expand service and involvement activities for and with low income area young people.
- Community development agencies should include the needs of the retarded as a factor in their planning.
- Voluntary family planning and birth control services should be available through community agencies.
- Facilities should be located for best service to all of a community's mentally retarded people.

On manpower for mental retardation programs

- Increased efforts should be made to bring both professional specialists and supportive workers into mental retardation programs.
- Specialists' functions should be evaluated with a view to transfer of as many functions as possible to trained supportive workers.
- Federal grants should be made to states to assist in volunteer service program development.
- Mental retardation programs should develop employee education and training programs.
- The federal government should develop a mental retardation program staff exchange activity.

On residential services for the retarded

- Improved standards and a system of accreditation for residential programs for the retarded should be developed.
- The federal government's Hospital Improvement and Hospital In-Service Training Programs should be expanded.
- A program for relocating and rebuilding obsolete residential facilities should be established.
- A system to give parents and guardians a free choice in selecting residential services should be established.
- A system of loans or grants should be established to help private organizations develop alternative forms of residential service for the retarded.
- Welfare agencies should earmark a portion of their resources for services to the retarded and their families.
- Mental health agencies should take leadership in developing services for the retarded who are emotionally disturbed.

Principal Publications of The President's Committee on Mental Retardation

MR 67: The Committee's first report. Outlines 10 areas in which citizen and agency action can produce progress in combating mental retardation.

MR 68: THE EDGE OF CHANGE. The Committee's second report. Covers grass-roots developments in mental retardation programs. Surveys needs and makes recommendations on residential services, manpower development and poverty-mental retardation links.

MR 69: TOWARD PROGRESS—THE STORY OF A DECADE. Surveys major mental retardation research and service developments of the 1960's, makes recommendations for programs and approaches to be developed during the 1970's.

HELLO WORLD! Popularly written general information booklet. Illustrates various kinds of mental retardation with case stories. Includes action tips for parents, community organizations, students, seekers of career and volunteer service opportunities.

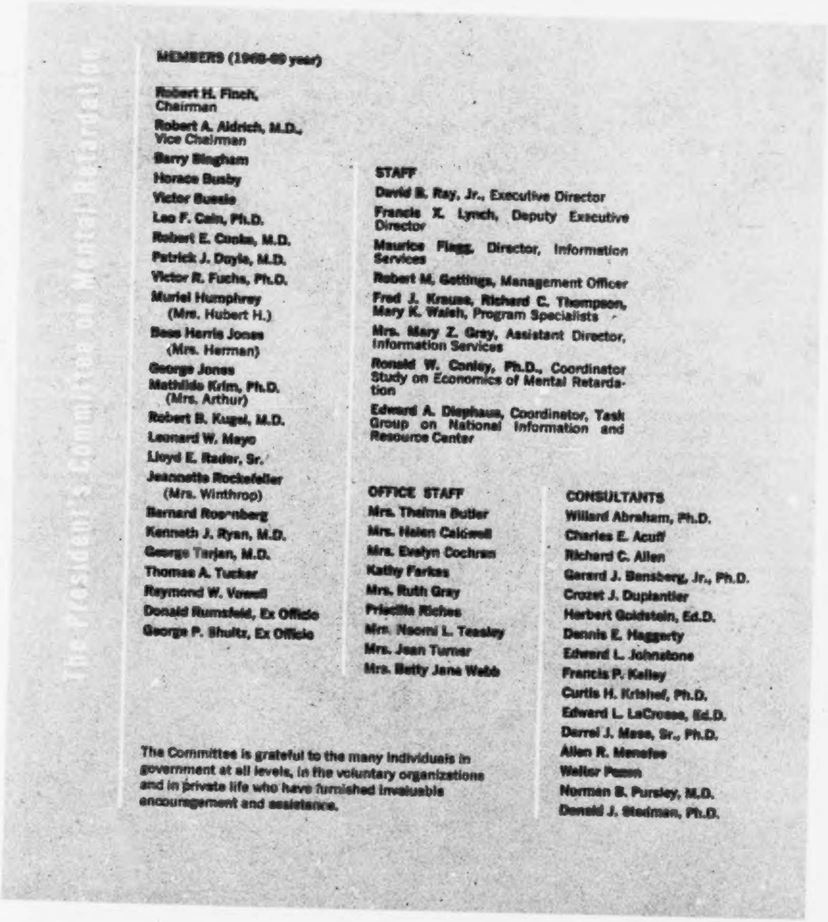
TO YOUR FUTURE . . . WITH LOVE. For youth and college students seeking meaningful volunteer and career opportunities.

THE MENTALLY RETARDED IN MODEL CITIES. Report of a workshop, with suggestions for planners.

CHANGING PATTERNS IN RESIDENTIAL SERVICES FOR THE MENTALLY RETARDED. A monograph on history, development, problems and possible future patterns of residential services for the retarded.

PCMR MESSAGE. The Committee's newsletter. 6 to 8 issues a year. Among features in recent issues have been articles on: mental retardation-related papers from the XII International Congress of Pediatrics; the future of residential service facilities; scientific research and mental retardation; a reporter's look at mental retardation's public image; the community volunteer's stake in mental retardation action; the retarded victims of deprivation.

INFORMATION OFFICE NEWS CLIPPING SERVICE. Topical clippings from the mental retardation field nationwide. 48 to 50 issues a year.



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The Committee is grateful to the many individuals in government at all levels, in the voluntary organizations and in private life who have furnished invaluable encouragement and assistance.

MENTAL RETARDATION

Construction Program

RESEARCH CENTERS
UNIVERSITY–AFFILIATED FACILITIES
COMMUNITY FACILITIES

Secretary's Committee on
Mental Retardation

U.S. DEPARTMENT OF
HEALTH, EDUCATION, AND WELFARE
Robert H. Finch, Secretary

Patricia Reilly Hitt, Assistant Secretary
for Community and Field Services

Washington, D.C. 20201
March, 1969

FOREWORD

Federal support for categorical construction programs is a relatively new principle. In fact, prior to 1963, no Federal legislation existed to support construction of facilities designed specifically for the mentally retarded.

Since the enactment in 1963 of the Mental Retardation Facilities and Mental Health Centers Construction Act (P.L. 88-164), three different but interrelated construction programs for the retarded have been initiated: Research Centers, University-Affiliated Facilities and Community Facilities. As of March 31,1969, a total of 12 Research Centers, 18 University-Affiliated Facilities, and 242 Community Facilities had been approved and funded.

These construction programs were designed to provide assistance in three areas of concern: continuing research into the causes and means of prevention of mental retardation; inter-disciplinary training of professional personnel for research and service careers in both present and newly emerging programs; and establishment of a network of facilities where the retarded can obtain services in their own communities.

This publication reviews the current status of these three construction programs for the mentally retarded.

Special acknowledgement is given to Dr. Michael Begab, National Institute of Child Health and Human Development and Mr. Vivian Hylton and Mr. Ronald Almack, Division of Mental Retardation, Rehabilitation Services Administration, for their contributions to this publication.

Patricia Reilly Hitt

(Mrs.) Patricia Reilly Hitt
Assistant Secretary for
Community and Field Services

INTRODUCTION

The Report of the President's Panel on Mental Retardation in 1962 resulted in a breakthrough of real significance for mental retardation programs. This Report was a culmination of the efforts of a group of distinguished Americans who studied the problem of mental retardation and reported on their findings. The Report outlined a number of areas for action, and provided a blueprint for planning and implementive programs of comprehensive services to the retarded. The Report in large measure was responsible for the subsequent enactment of a number of Federal laws affecting the retarded, including authority for new construction programs.

Subsequent to issuance of the Report, a special message on mental retardation and mental health was sent to Congress in 1963. The message outlined areas of concern and suggested possible approaches. Three areas given special attention were research and prevention, manpower and community based services. In the same year Congress enacted the first Federal categorical construction programs for the mentally retarded: "The Mental Retardation Facilities and Mental Health Centers Construction Act of 1963" (P.L. 88-164).

Briefly, P.L. 88-164 authorized appropriation of $329 million over a five-year period to provide: grants for construction of mental retardation facilities; grants for training professional personnel in the education of the handicapped and grants for conducting research relating to the education of the handicapped.

Title I, Part A, of P.L. 88-164, authorized project grants for the construction of public or nonprofit centers for research that would develop new knowledge for preventing and combatting mental retardation.

Title I, Part B, authorized project grants to assist in the construction of public or nonprofit clinical facilities for the mentally retarded, associated with a college or university, which: (1) provide, as nearly as practicable, a full range of inpatient and outpatient services; (2) aid in demonstrating provision of specialized services for diagnosis, treatment, training, or care; and (3) aid in the clinical training of physicians and other specialized personnel needed for research, diagnosis, treatment, training or care.

Title I, Part C, authorized Federal grants to States to assist in the construction of specially designed public and nonprofit community facilities to provide diagnosis, treatment, education, training, custodial (personal) care, and sheltered workshops for the retarded.

The Mental Retardation Amendments of 1967 (P.L. 90-170) provided for a new grant program to pay a portion of the costs for compensation of professional and technical personnel in community facilities for the mentally retarded.

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MENTAL RETARDATION RESEARCH CENTERS

Research and research training in mental retardation and related aspects of human development present unique demands in terms of facilities and resources. Recognition of these needs led, in 1963, to legislation authorizing construction grants for facilities in which biological, medical, social, and behavioral research relating to human development could be conducted to assist in finding the causes and means of prevention of mental retardation and, for finding means of ameliorating its effects.

Acceptance of applications for construction grant awards under the Act authorizing the Mental Retardation Research Centers closed on July 1, 1967. During the authorized four years of the Mental Retardation Research Center Construction Grant Award Program a total of twelve centers were awarded to outstanding scientific institutions. During its construction phase this program was jointly administered by the Division of Research Facilities and Resources and The National Institute of Child Health and Human Development (NICHD). Continuing responsibility for the research program in the centers is carried on by NICHD.

The facilities constructed through the Mental Retardation Research Center Program will provide research facilities in particular environments where a cohesive program of research and research training can be accomplished. Most of the centers are large complex facilities in settings where a broad spectrum of research on mental retardation can best be carried out. A small number of specialized centers which have a concentrated scientific focus on a particular aspect of mental retardation are also supported by the program.

UNIVERSITY OF WASHINGTON, SEATTLE, WASHINGTON

The Mental Retardation Program at the University of Washington is a multidisciplinary university-wide endeavor involving the Medical School, Dental School, School of Nursing, School of Social Work, the College of Education and the Departments of Psychology and Sociology.

Research in the biological sciences will include developmental biology, perinantal biology and the neurological sciences. Behavioral studies will include individual behavior under carefully controlled environmental conditions, family and peer group interactions, and applied research on testing of educational and treatment techniques. The facility will also be utilized for research on new methods and materials for the retarded.

This Center will feature outpatient and residential facilities for comprehensive clinical studies of retarded children and will provide research training programs to prepare physicians and professionals in the health related disciplines for research in mental retardation and related aspects of human development.

Total cost of project:	$8,290,970
Federal Share:	6,250,616
Date of Award:	October, 1964
Estimated completion date:	1969

University of Washington, Seattle, Mental Retardation and Child Development Center

ALBERT EINSTEIN COLLEGE OF MEDICINE, YESHIVA UNIVERSITY, NEW YORK, NEW YORK

This program will be a joint effort of the Departments of Obstetrics and Gynecology, Pediatrics and Psychiatry. It will concern itself with research problems involving the total human organism, the family and the community with special emphasis on factors leading to mental retardation.

Studies in developmental biology will be conducted at all levels, including molecular and enzymatic studies of the organ systems. Research will also be undertaken in the behavioral and social sciences and ecology.

The College of Medicine has working arrangements with the Edenwald School, a residential treatment center for retarded children, and with the New York City Hospital which will enable them to translate new research findings into patient care.

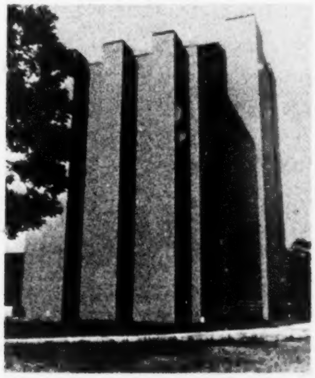
Total cost of project:	$5,124,815
Federal Share:	3,304,000
Date of Award:	October, 1964
Estimated completion date:	1969

CHILDREN'S HOSPITAL, CINCINNATI, OHIO

This Research Center will focus on biomedical research. In addition to its pediatric researches the program will include teratology and genetics, physiology, biochemistry, and clinical research. It will stress basic research and research training, and the development of diagnostic and treatment techniques.

Areas of study will include malformations resulting from altered environment during the developmental period and genetic abnormalities, inborn metabolic errors, and various studies of the effects of drugs and infection on the fetus and mother.

Total cost of project:	$3,011,210
Federal Share:	1,724,000
Date of Award:	July, 1965
Completion date:	July, 1967



Children's Hospital, Cincinnati,
Institute for Developmental Research

WALTER E. FERNALD STATE SCHOOL, WALTHAM, MASSACHUSETTS

This Center is located on the grounds of an institution for the retarded and will place heavy emphasis on the retarded person as the object of study. Interchange with investigators in other fields will be encouraged, and research will focus on prevention and amelioration. Among the disciplines included in this research program are neurology, psychiatry, pediatrics, epidemiology, experimental psychology, cytogenetics and education. An unusual feature of this project is the close cooperation between the Fernald School, Massachusetts General Hospital, and the Harvard Medical School.

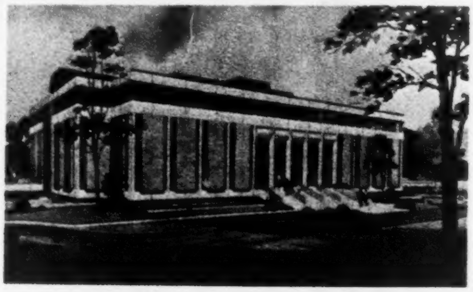
Total cost of project:	$1,790,000
Federal Share:	827,000
Date of Award:	May 1965
Estimated completion date:	1969

GEORGE PEABODY COLLEGE FOR TEACHERS, NASHVILLE, TENNESSEE

This College has a long and productive history of research and training in the field of mental retardation but in a circumscribed area of the behavioral sciences. The new Center will make possible the expansion of interdisciplinary research efforts and research training for a wider range of behavioral scientists and for collaborative research with biomedical disciplines at Vanderbilt University.

In the newly created Division of Human Development, the program will primarily be directed at the educational, psychological and sociological aspects of mental retardation with strong emphasis on cultural deprivation. The uniqueness of this research program lies in its relatively narrow but powerful thrust on these vital dimensions of the problem.

Total cost of project:	$3,543,547
Federal Share:	2,492,900
Date of Award:	May, 1965
Completion date:	November, 1967



George Peabody College for Teachers,
Nashville, Tennessee

UNIVERSITY OF CALIFORNIA, LOS ANGELES, CALIFORNIA

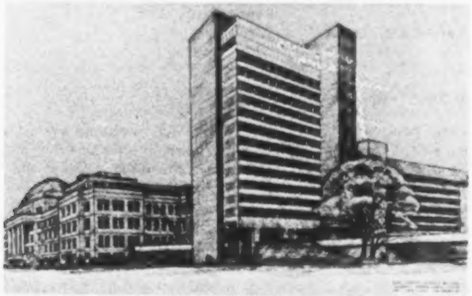
The main focus of the research program in this Center will involve a combined biological and behavioral approach to the problem of mental retardation. It envisions cooperative studies among the Departments of Psychiatry, Neurology, Pediatrics, Biochemistry and other Divisions within the Medical School, as well as the Departments of Sociology and Psychiatry. Collaborative studies of a basic and clinical nature related to mental retardation will be undertaken.

The University has also received approval for the construction of a clinical facility for training and demonstration under Part B, Title I of the P. L. 88-164. These activities will be closely coordinated with those of the research center.

Total cost of project:	$2,588,970
Federal Share:	1,710,000
Date of Award:	January, 1966
Estimated completion date:	1969

CHILDREN'S HOSPITAL MEDICAL CENTER, BOSTON, MASSACHUSETTS

This Center is closely affiliated with the Harvard Medical School and proposes an interdisciplinary research program directed toward the understanding, prevention and amelioration of the handicapped and the mentally retarded. The research team will include representation from experimental neurological sciences, behavioral sciences, genetics, metabolism and clinical research.



Children's Hospital Medical Center,
Boston, Massachusetts

This action is the largest single commitment in the Institution's history to research in a given field.

Total cost of project:	$4,140,337
Federal Share:	2,470,000
Date of Award:	January, 1966
Estimated completion date:	1970

UNIVERSITY OF KANSAS, LAWRENCE, KANSAS

The University of Kansas has a unique plan for the location of three research and research training units - at the Kansas Medical Center, the main campus of the University at Lawrence, and the Parsons State Hospital and Training Center, an institution for the retarded.

The long-range multidisciplinary research program is broadly conceived and focuses on biomedical and behavioral research relevant to mental retardation. Each of the three settings will emphasize a specific area of research. Studies at the Medical Center will include reproductive physiology, biochemistry, neurophysiology and fetal and neonatal pathophysiology. Studies on learning, language, and social behavior will also be conducted. At the Lawrence campus, research will feature residential and preschool studies of behavior and the processes of socialization, communication, and learning. The program at Parsons will stress research in training of children with deficits in language, socialization and adaptive behavior, in academic attainment and vocational skills.

Total cost of project:	$2,921,978
Federal Share:	2,150,000
Date of Award:	September, 1965
Estimated completion date:	1969

UNIVERSITY OF COLORADO, DENVER, COLORADO

Strong research programs in neurophysiology, neuropharmacology, behavioral sciences, developmental pediatrics, cytogenetics, nutrition, developmental and lipid biochemistry, and neurochemistry form the basic science research core of the Colorado center.

The Wheatridge State Home and Training School, the Colorado mental retardation training facility, and State and community health resources will provide additional resources for research through a coordinated program. Special studies in family and community health will be possible through these extra resources. Epidemiological and population genetic studies will be conducted among the special populations resident in Colorado and the Southwest.

Total cost of project:	$442,647
Federal Share:	296,100
Date of Award:	December, 1966
Completion date:	1968

UNIVERSITY OF NORTH CAROLINA, CHAPEL HILL, NORTH CAROLINA

The University of North Carolina Child Development and Mental Retardation Research Center plans a broad program of research involving medical, psychological, educational and social sciences.

Two separate but administratively unified facilities will be constructed. The medical research facility will house a comprehensive research program including research in the clinical and basic sciences of medicine and health related disciplines.

The psycho-educational facility will consist of a unique arrangement of educational and care facilities with supporting research laboratories. The central research theme will be long-term, longitudinal studies of retarded children and children at risk of becoming retarded. Beginning in infancy or early age and continuing through the elementary school years of the children will be provided with a carefully engineered program and environment designed to enhance their intellectual, social and emotional development. Medical research here will include studies of the impact of optimal health care and the consequences of infectious diseases on development.

Total cost of project:	$3,423,241
Federal Share:	2,439,400
Date of Award:	September, 1966
Estimated completion date:	1970

UNIVERSITY OF CHICAGO, CHICAGO, ILLINOIS

An award for moveable research equipment was made to the University of Chicago to assist in equipping their Joseph P. Kennedy, Jr. Mental Retardation Research Center located in Wyler Children's Hospital. The research center is contiguous with the Chicago Lying-in-Hospital which provides a resource for studies of prematurity and obstetrical conditions leading to retarded development.

Research in the center will focus on cytogenetics and population genetics, enzyme development, neurological and hematological investigations, biochemistry, virology, respiratory physiology, and developmental studies.

Moveable research equipment award only.

Amount of Award:	$59,300
Date of Award:	September, 1966
Completion date:	March 1967

. UNIVERSITY OF WISCONSIN CENTER, MADISON, WISCONSIN

The University of Wisconsin Center plans a broad, comprehensive research program involving the biomedical, behavioral, social and educational sciences. The Biomedical Sciences Unit will provide for research in neurophysiology, neurometabolism and nutrition, and neuroendocrinology and reproduction. Programs proposed for the Behavioral and Social Sciences Unit will focus on genetic and environmental factors in infant development; basic behavioral developmental processes; learning in educational situations; communication processes; and, family and social factors. The Central Wisconsin Colony will be closely integrated into the research and research training activities to assure coverage of the problems of the institutionalized retardate. A University-Affiliated Facility and program under common administration will provide a close relationship of center activities to clinical training.

Total cost of project:	
Federal Share:	$2,263,000
Date of Award:	January 26, 1967
Estimated completion date:	1971

APPROPRIATIONS AND APPROVED APPLICATIONS FOR
MENTAL RETARDATION RESEARCH CENTERS
December 31, 1968

FISCAL YEAR	APPROPRIATION	APPLICATIONS APPROVED	FEDERAL SHARE
TOTAL..........	$26,000,000	12	$25,986,316

Institutions	Total Cost	Federal Share	Estimated and/or Completion Date
University of Washington, Seattle, Washington	$8,290,970	$6,250,616	1969
Albert Einstein College of Medicine, Yeshiva University New York, New York	5,124,815	3,304,000	1969
Children's Hospital Cincinnati, Ohio	3,011,210	1,724,000	July 1967
Walter E. Fernald State School, Waltham, Massachusetts	1,790,000	827,000	1969
George Peabody College for Teachers, Nashville, Tennessee	3,543,547	2,492,900	Nov. 1967
University of California Los Angeles, California	2,588,970	1,710,000	1969
Children's Hospital Medical Center, Boston, Massachusetts	4,140,337	2,470,000	1970
University of Kansas, Lawrence, Kansas	2,921,978	2,150,000	1969
University of Colorado, Denver, Colorado	442,647	296,100	April 1968
University of North Carolina, Chapel Hill, North Carolina	3,423,241	2,439,400	1970
University of Chicago, Chicago, Illinois	(Moveable Research Equipment Award)	59,300	1967
University of Wisconsin, Madison, Wisconsin	7,000,000*	2,263,000	1971
TOTAL	$39,647,715	$25,986,316	

* - Includes Estimated Cost of Both Research Center and University-Affiliated Facility.

UNIVERSITY-AFFILIATED FACILITIES CONSTRUCTION PROGRAM FOR THE MENTALLY RETARDED

The program of Federal assistance for the construction of University-Affiliated Facilities for the mentally retarded was authorized under P.L. 88-164, "The Mental Retardation Act of 1963", and extended until 1970 under the Mental Retardation Amendments of 1967 (P.L. 90-170). This program provides grants for the construction of University-Affiliated Facilities with programs for the mentally retarded and persons with related neurological handicapping conditions. Eighteen university-affiliated facilities have been approved for funding.

The primary purpose of the University-Affiliated Facilities Construction program is to provide facilities for the clinical training of professional and technical personnel essential for diagnostic services and the care, education, training, and rehabilitation of the mentally retarded individual and his family. Each facility is encouraged to conduct a comprehensive interdisciplinary training program integrating and coordinating the full range of professional and technical personnel concerned with mental retardation so that each discipline may be fully familiar with its own contributions and those of related disciplines to the total effort in the field of mental retardation. A full range of individual and group services and demonstration of new techniques and concepts in services for the mentally retarded are considered important elements in University-Affiliated Facility programs, and research incidental or related to activities conducted within the facility is authorized.

This construction program is administered by the Division of Mental Retardation, Rehabilitation Services Administration, Social and Rehabilitation Service, U. S. Department of Health, Education, and Welfare. The following descriptions review the types of facilities and programs which have been supported with these funds and the current status of their construction.

1. UNIVERSITY OF ALABAMA MEDICAL CENTER AT BIRMINGHAM AND TUSCALOOSA, ALABAMA

The University of Alabama program is based at two locations, one in Birmingham and the other at Tuscaloosa.

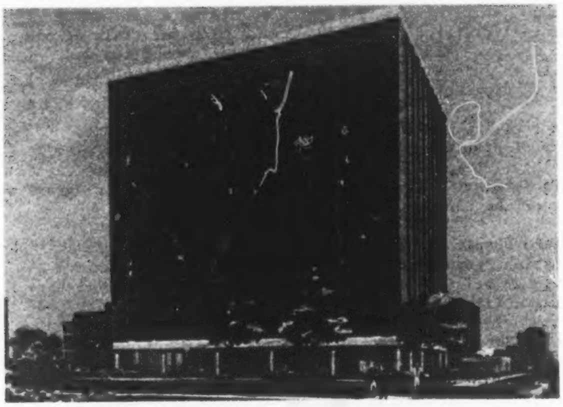
The Medical School at Birmingham presently maintains a variety of services for the mentally retarded which serve as a base for training and will be expanded to increase diagnostic and evaluation capability and capacity coupled with an intensive program of treatment and professional training in various disciplines.

The Tuscaloosa facility presently provides specialized graduate training in a variety of disciplines including clinical psychology, experimental psychology, social work, special education, and communication disorders. Interdisciplinary clinical, research and educational programs were developed as a part of the Center program.

The Partlow State Hospital, located adjacent to the Tuscaloosa campus, with an inpatient population of 2,000, will utilize to maximum advantage the behavioral sciences faculty at the main University. Interdisciplinary training utilizing joint appointments in the University and the facility and the dual relationship, with the University and Partlow School, will result in the application of knowledge of recent advances in research, training and service for the mentally retarded.

Training programs are coordinated through an advisory council consisting of the Deans of Medicine, Dentistry, Arts and Sciences, Education and the Graduate School. An interdisciplinary advisory committee consisting of the Chairman of the subgroups in the various schools and colleges of the University supervises training. The council, the committee and the Directors of the Tuscaloosa and Birmingham facilities are under the administrative direction of the Vice President of the University for Medical Affairs.

Total Cost:	$2,907,326
Federal Share:	2,180,494
Date of Award:	November 1965
Completion Date:	Tuscaloosa: October 1968 Birmingham: January 1969



University of Alabama Medical Center, Birmingham, Alabama

2. UNIVERSITY OF CALIFORNIA, NEUROPSYCHIATRIC INSTITUTE,
LOS ANGELES, CALIFORNIA

The Mental Retardation University-Affiliated Facility of the University of California Neuropsychiatric Institute is housed in a new four-story addition to the existing UCLA Medical School Complex.

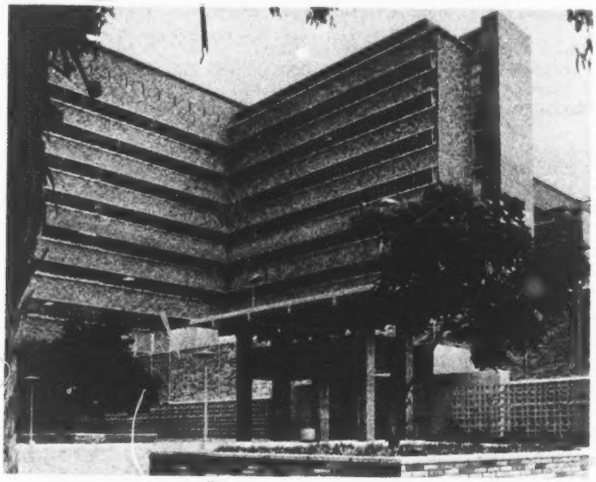
The Mental Retardation Unit provides three 20-bed wards, one for young severely retarded children, one for ambulatory retarded children, and one for older children with varying degrees of retardation. The fourth floor houses the school facilities.

All children coming to the UCLA Medical Center, both inpatients and outpatients, are screened in the general pediatric clinic, and mentally retarded patients are referred to the Neuropsychiatric Institute for extensive diagnostic studies and evaluation. The outpatient department functions as a part of the total program at the present time. The major effort in mental retardation has been based at the Pacific State Hospital at Pomona, and the center will provide a facility to bring widely distributed services and training sites together.

The inpatient and outpatient evaluation and treatment program is utilized to support the interdisciplinary training effort that is being undertaken. Students in fields such as psychiatry, pediatrics, other branches of medicine, psychology, social work, special education and nursing are receiving training. All students have an opportunity for close interaction with extensive research programs carried out in the Center for Research in Mental Retardation and Related Aspects of Human Development funded under Title I, Part A, P.L. 88-164.

The State Department of Mental Hygiene will provide basic research and training support for the center. The Schools of Education and Social Work of UCLA are associated with the Pacific State Hospital in coordinated research efforts. The interdisciplinary training program is broadly based within the center and is allied with the interdisciplinary research training program supported by the State and the U.S. Public Health Service.

Total Cost:	$6,330,000
Federal Share:	2,638,335
Date of Award:	July 1965
Completion Date:	December 1968



University of California, Neuropsychiatric Institute
Los Angeles, California

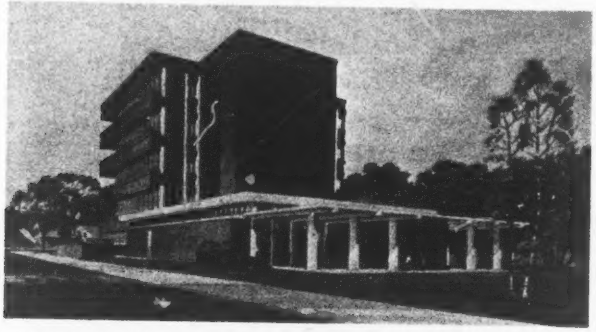
3. JOHN F. KENNEDY CHILD DEVELOPMENT CENTER AND B. F. STOLINSKY RESEARCH LABORATORIES, UNIVERSITY OF COLORADO, DENVER, COLORADO

The Center is adjacent to an existing day care center located on the main campus of the Medical School. It is a three story building providing space for pediatricians, nurses, clinical psychologists, social workers, nurses, nutritionists, dentists, audiologists and speech therapy personnel in training. A special feature of the Center is a large indoor play area and school room where children may be observed.

Students from the Schools of Social Work and Psychology of the Denver University will be assigned to the Center. Students from the Departments of Physical Medicine and Special Education of Colorado State University will also be provided with training opportunities in an interdisciplinary teaching environment

The importance of the Center in the overall State effort is exemplified by the Center's designation as a Regional Center in Mental Retardation. Training programs are coordinated through the Director of the Center who has a Medical School appointment. Interdisciplinary research and clinical efforts in the Stolinsky Laboratories associated with the Center are being conducted to discover the causes, prevention and treatment of developmental deviations and their attendant emotional disorders.

Total Cost:	$602,884
Federal Share:	369,000
Date of Award:	January 1966
Completion Date:	July 1968



John F. Kennedy Child Development Center and B. F. Stolinsky Research Laboratories, University of Colorado, Denver, Colorado

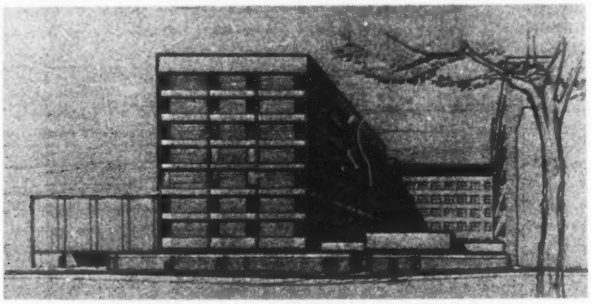
4. GEORGETOWN UNIVERSITY, WASHINGTON, D. C.

The University-Affiliated Center, which is an integral part of the Medical School complex, will be directed toward meeting the needs of the training effort related to: (a) more complete diagnostic evaluations (b) longitudinal management and rehabilitation of the mentally retarded (c) training of medical students, physicians and nurses. The social behavioral components in training involve other local universities, e.g., psychology students come from Catholic University, special education students from George Washington University, and social work students from Howard University under a consortium agreement to assure interdisciplinary training in which training content is determined by the affiliated universities. A small preschool nursery is staffed by the St. Johns Developmental School, a community facility. The District of Columbia, Virginia, and Maryland Departments of Vocational Rehabilitation will provide patient prevocation evaluations and will be closely allied with the Center.

Emphasis in the intramural phase of the program will be on early diagnosis and comprehensive programming for the preschool child. Diagnostic classrooms will be an essential resource for the program, with a special interest in individuals having both auditory and visual handicaps. Training in inpatient care will be provided in a 29-bed unit.

The Center will offer training in the fields of social work, special education, sociology, theology, and law, in addition to the biomedical professions, in an interdisciplinary approach to the problems of mental retardation. An extramural program directed at existing community resources of high quality will allow training programs and services to be integrated into the comprehensive needs of the mentally retarded in the metropolitan Washington area.

Total Cost:	$2,000,000
Federal Share:	1,500,000
Date of Award:	February 1965
Estimated Completion Date:	October 1969



Georgetown University, Washington, D. C.

5. UNIVERSITY OF MIAMI, MIAMI, FLORIDA

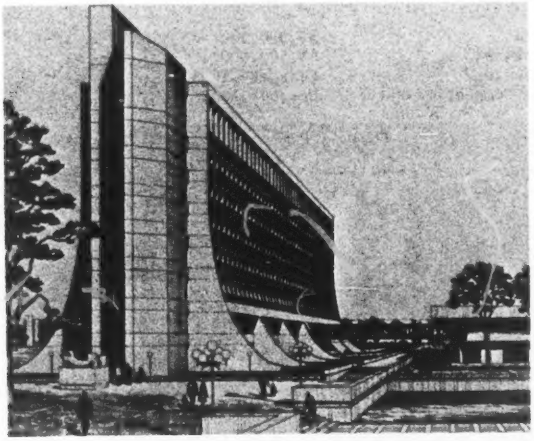
The Mailman Child Development Center will be located on the campus of the School of Medicine of the University of Miami, within the immediate vicinity of the Jackson Memorial Hospital and the National Children's Cardiac Hospital, which are teaching hospitals for the Medical School.

The Center provides an opportunity to make training in mental retardation a part of the learning experience of all medical, nursing, psychology, social work, special education, speech and law students. Students from the University of Miami, Florida State University, Barry College and the University of Florida will participate in the training programs. The programs will be devoted to seeking the causes and means of prevention as well as the methods of ameliorating psycho-social and medical effects of mental retardation and other handicapping conditions.

Training programs are under the supervision of a Director appointed by the President of the Main University. The Director serves as chairman of the interdisciplinary training committee whose members are selected by the Dean of the appropriate schools or colleges in the University.

Patients are admitted by referral from community and social agencies as well as private physicians. They will range in age from infancy to the older adults, and all levels of retardation will be seen and evaluated. The bulk will come from Dade and Broward Counties; however, there will be no geographical restrictions on admission.

Total Cost:	$4,872,575
Federal Share:	3,054,432
Date of Award:	November 1966
Estimated Completion Date:	December 1970



University of Miami, Miami, Florida

6. GEORGIA RETARDATION CENTER, GEORGIA DEPARTMENT OF PUBLIC HEALTH, ATLANTA AND ATHENS, GEORGIA

A facility located in Atlanta and a satellite facility to be built in Athens on the University of Georgia campus will comprise the Center.

Atlanta

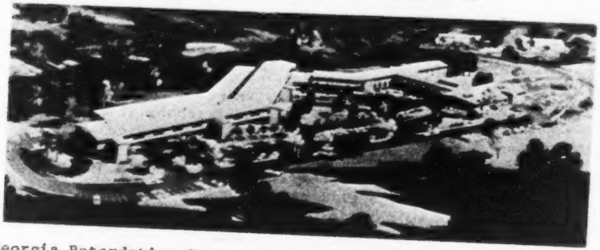
The University Affiliated Center for the mentally retarded will be a part of a large State residential Mental Retardation Center in Atlanta This comprehensive residential facility will serve approximately 1,000 resident retardates, and provide day care services for an additional 500 retardates. The following colleges and universities will be affiliated in the training programs of the Atlanta facility in the disciplines as indicated: 1. Atlanta University - special education and social work; 2. Interdenominational Theological Center - religious therapy; 3. University of Georgia - speech and hearing, recreation for the handicapped, special education, child development, guidance and counseling, vocational rehabilitation, psychology, and sociology; and 4. Emory University - pediatrics, psychiatry, physical medicine, physical therapy, occupational therapy, special education, nursing, psychology, sociology, religious therapy, and speech and hearing. All of the affiliated training programs will be at the graduate level, and the facilities will be made available insofar as practicable for undergraduate instruction.

Training programs are conducted through an an Advisory Board for Training chaired by the Assistant to the Superintendent for the Georgia Retardation Center with members representing each university or college affiliated with the Cente

Athens

The Athens Facility at the University of Georgia will accommodate 40 short term residents and 40 retardates in the day care program. The Facility well serve as a laboratory to teach diagnostic and therapeutic measures for speech pathologists in language, speech, and hearing problems of the mentally retarded. The University of Georgia, Department of Psychology presently conducts a psychological clinic as part of the program for training of clinical psychologists.

Total Cost:	Atlanta	$17,387,852
	Athens	2,137,248
Federal Share:	Atlanta	$1,206,450
	Athens	1,887,713
Date of Award:	Atlanta	June 1969
	Athens	June 1969
Estimated Completion Date:	Atlanta	June 1969
	Athens	December 1969



Georgia Retardation Center, Dekalb, Georgia

7. INDIANA UNIVERSITY MEDICAL CENTER
INDIANAPOLIS AND BLOOMINGTON, INDIANA

This Center for Mental Retardation consists of two facilities, one at the Indiana University Medical Center, Indianapolis, and the other at the Indiana University Campus in Bloomington, Indiana.

Primary training responsibility for student trainees will be under the direction of the appropriate departments. The program will be administered by two working committees and a steering committee under the direction of the Vice President for Research and Advanced Study at Indiana University. These working committees are the Professional Advisory Committee, Riley Child Development Center, and the Professional Advisory Committee.

Riley Hospital Child Development Facility, Indianapolis

This Facility will become a part of the Riley Hospital for Children, which is the only hospital in the State devoted entirely to the care of children. It has served as a referral Center for all difficult cases of pediatric diagnosis and treatment, and over 50% of the children are referred from throughout the State to the hospital. At least 40% of the children seen in the outpatient clinic are diagnosed as mentally retarded. Family interactions that are critical to mentally retarded youngsters have long been explored.

The physical plan of the Facility takes into account the latest trends in patient care, particularly ambulatory services. The consultative diagnostic and treatment clinic serves as a comprehensive consultation service to physicians within the State and also serves as a major educational activity at the Medical School. Pediatric residents are assigned to the Facility for three-month periods, and senior medical students are assigned to the clinic as part of a six-week pediatric training program. Students from the School of Nursing and the allied health professions, i.e., social work, psychology, audiology, occupational therapy, and speech therapy, attend sessions within the Facility.

As each patient is diagnosed and evaluated, an effort is made to develop continuity care and the designation made of specialty clinics which will be beneficial to the retardate after his return to the referring physician or his home.

Indiana University Developmental Training Facility, Bloomington

This Facility is located adjacent to the laboratory school.

The Bloomington Facility will house 48 children in eight "home units" arranged as "row houses." Each unit will be autonomous in that it will have the normal features found in a home and an attached apartment for cottage parents who will provide a home atmosphere and individuality for each unit.

Coodination of training programs between the Riley Hospital Child Development Facility and the Indiana University Developmental Training Facility will be established. The Bloomington Facility will profit from consultation and guidance received from the Indianapolis Facility in the areas of pediatrics, neurology, psychiatry, nursing, and social work. Likewise, the Indiana University at Bloomington will provide consultation to the Riley Facility in the behavioral sciences, speech and hearing, special education, counseling and recreation.

Total Cost:	$4,277,635
Federal Share:	3,157,231
Date of Award:	December 1965
Completion Dates:	Riley Hospital: January 1970 Bloomington: August 1969

Indiana University Developmental Training Facility, Bloomington, Indiana

8. UNIVERSITY OF KANSAS AND PARSONS STATE HOSPITAL: LAWRENCE, KANSAS CITY, AND PARSONS, KANSAS

The University-Affiliated Facility to be constructed in Kansas will consist of three buildings - one to be located at the University of Kansas at Lawrence, one at the Kansas University Medical Center at Kansas City, and one at the Parsons State Hospital. These Facilities will be adjacent or additive to the three buildings comprising the Kansas Center for Research in Mental Retardation and Human Development currently under construction. The multiple locations of the Kansas combined Center facilities make possible the utilization of varied research and clinical training resources. The three locations allow for the exploitation of resources of: (1) the academic community with its faculty and student population; (2) a modern medical center located in the heart of a metropolitan area; (3) a progressive residential construction project. Construction funds for the Kansas Center for Research in Mental Retardation came from Title I, Part A, P.L. 88-164. The combined Center in Mental Retardation will be coordinated by and administratively responsible to the Bureau of Child Research of the University of Kansas. Since 1957, the Parsons State Hospital, the Kansas University Medical Center, and the Bureau of Child Research have been engaged in behavioral and biological research and interdisciplinary training on a cooperative basis. The new construction will make possible the expansion and long-term projection of these activities.

The Medical Center serves the State of Kansas and adjoining areas as a major referral center for individuals with all types of behavioral and diagnostic problems. The University-Affiliated Facility will provide service and training programs on each campus to improve comprehensive evaluation for patients. In addition both patients and their families will have access to a comprehensive longitudinal care program centrally directed.

Training programs are conducted in an interdisciplinary environment in pediatrics, special education, psychiatry, nursing, speech and hearing, psychology, dietetics and nutrition, and social service.

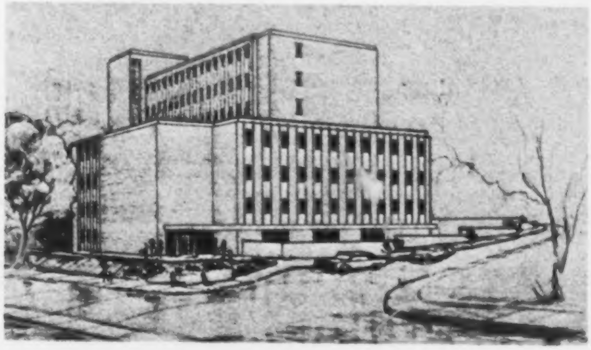
The Lawrence Facility will draw upon all of the resources of the University and will include a large number of trainees which will serve as a primary resource for recruitment and for pre-professional training. The staff of the Lawrence Facility will share responsibilities at the other two settings in the training of disciplines mentioned above, and an emphasis on developmental factors will be stressed in the following areas: parent counselling, behavioral training, the importance of community and environment, social and educational skills, and learning processes.

Parsons State Hospital and Training School

The Facility at the Parsons State Hospital and Training School will consist of a medical evaluation treatment section, a behavioral and evaluation section, and a section for audio-visual production. The plan for training clinical specialists at both Parsons and Kansas City will enable the training coordinators to draw upon resources of both the Research Center and the University-Affiliated Facility.

An administrative and coordinated structure has been organized in such a way that the levels of training responsibility are specified. A training director at each Facility will be responsible to the Center Director, stationed on the Lawrence Campus. The training staff will stress the importance of interdisciplinary training and the need for proper utilization of inter-campus resources.

Total Cost:	$3,860,000
Federal Share:	2,729,400
Date of Award:	April 1969
Estimated Completion Date:	December 1970



University of Kansas University-Affiliated Facility

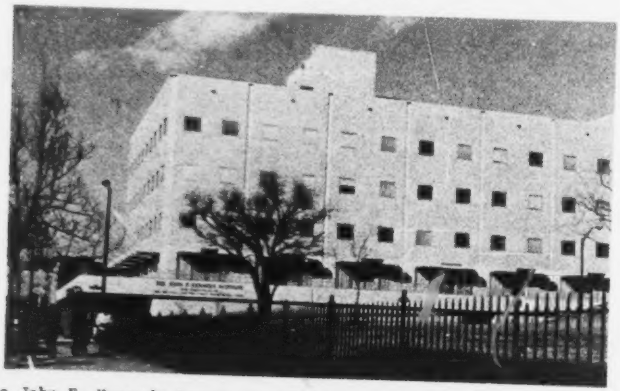
9. THE JOHN F. KENNEDY INSTITUTE (CHILDREN'S REHABILITATION INSTITUTE) BALTIMORE, MARYLAND

The Children's Rehabilitation Institute is affiliated with the Johns Hopkins University Medical School and faculty recognition and status has been given to the Institute staff. The Institute is placing major emphasis on the following 3 program areas of greatest concern: (a) recruitment of high-caliber students and personnel from all disciplines to the field of mental retardation, (b) providing broader training and concepts for all Johns Hopkins medical, nursing and professional personnel who come in contact with the retarded and (c) helping to foster interdisciplinary understanding of the problem of mental retardation in the medical school, university, and the community.

The program within the Facility stresses the importance of the habilitation of the mentally and physically handicapped child. Special emphasis is placed on the treatment of both the child and family by flexible use of inpatient and outpatient services with the primary aim of returning the patient to the community as a functioning member of society. The Institute makes full use of the multidisciplinary clinic approach by providing a full range of diagnostic, evaluation and therapeutic services. Such services help develop a better understanding of the problem and make possible better long-term management of the child by the family.

An experimental school with a flexible curriculum and program for students ranging in age from five through twenty-one years is included in the institute. The school program includes prevocational training, sheltered workshop and work study programs. Residential patient care as well as training for parents is being provided in two residential units where parents are encouraged to live for a few days in order to obtain instruction as to the special needs and best methods of handling their particular child.

Total Cost:	$3,147,000
Federal Share:	2,360,250
Date of Award:	February 1965
Completion Date:	November 1967



The John F. Kennedy Institute (Children's Rehabilitation Institute)
Baltimore, Maryland

10. THE CHILDREN'S HOSPITAL MEDICAL CENTER, BOSTON, MASSACHUSETTS

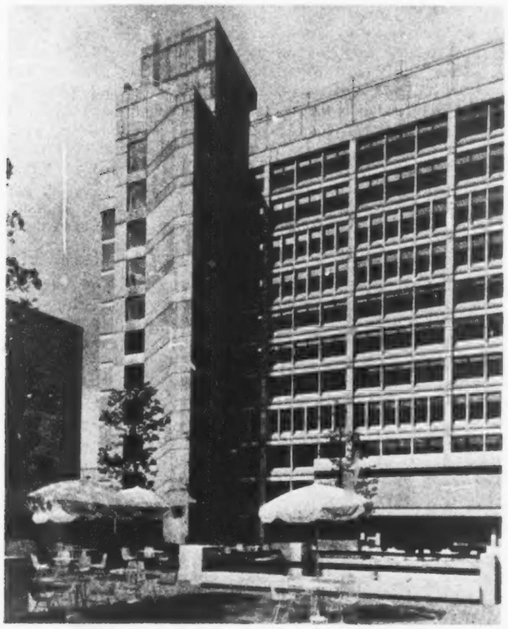
The Children's Hospital Center is the principal pediatric teaching hospital of Harvard University and a good source for securing referrals of patients who are mentally retarded. The Center serves as a teaching facility in social service, psychology, physical therapy, audiology, and special education for trainees assigned from Simmons College, Northeastern University, Wheelock College and Boston University. In 1929 the Children's Hospital Center created the first inpatient unit in the country where retarded children could be studied and evaluated by a team composed of pediatricians, neurologists, psychologists, and social workers with consultation available in other appropriate specialties including orthopedic surgery, psychiatry, and neurosurgery. The School of Nursing already provides teaching in the care of the mentally retarded. The Simmons College School of Physiotherapy is based at the Children's Hospital with special training being provided for the retarded child with orthopedic handicaps. Teaching in the field of communication disorders is provided. The University-Affiliated Facility is located in the Children's Hospital Medical Center complex.

Patients of the University-Affiliated Facility will be referred by various clinics and divisions of the hospital and by physicians and community agencies. The Children's Hospital Center serves most of the New England region and is a community hospital for a significant portion of the pediatric population in the Boston area. Where additional consultation in neurology, psychiatry, neurosurgery, otolaryngology, and orthopedic surgery is required, these services will be provided. The University-Affiliated Facility provides a nursery school for intensive observation or for diagnosis and evaluative purposes. After multiple studies have been concluded, evaluation of the patient and needs of family will be discussed and determined and a definitive program will be established.

The University Affiliated Facility maintains close liaison with several schools specializing in the training of nursery school teachers and programs of special training of teachers in the field of mental retardation. A modest program in vocational counseling, under the auspices of the Society for Crippled Children, has been in effect for the past several years.

The Facility is principally staffed by the departments of medicine, psychiatry, communication disorders, neurology and the divisions of psychology and speech and hearing of the Hospital Center. Affiliated training programs with other universities are supervised through the director of the Center with the appropriate heads of departments.

Total Cost:	$1,276,500
Federal Share:	863,250
Date of Award:	July 1965
Completion Date:	December 5, 1967



Children's Hospital Medical Center, Boston, Massachusetts

11. EUNICE KENNEDY SHRIVER CENTER, WALTHAM, MASSACHUSETTS

The Walter E. Fernald State School for the Mentally Retarded, which is affiliated with the Massachusetts General Hospital and through it, with Harvard University, is the site of both a University-Affiliated Facility and a Center for Research on Mental Retardation. The Center for Research received a separate award of funds under Part A of P.L. 88-164. These two new units make up the Eunice Kennedy Shriver Center. The Center has two main purposes:

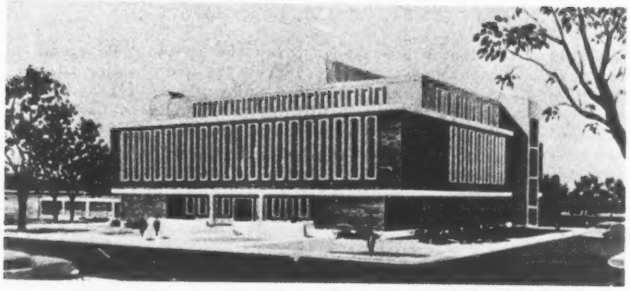
(1) To establish research and professional training programs in all the disciplines concerned with the care of the retarded; and

(2) To utilize the talents and accomplishments of the research and professional training staff to develop outstanding service programs for both the outpatient and the residential units.

Research programs are conducted in biochemistry, dentistry, epidemiology, genetics, neurology, neuropathology, pediatrics, psychology, psychiatry and special education. There are professional training programs in these same disciplines and also neuroradiology, nursing, nutrition, occupational therapy, opthalmology, physical therapy, social service, speech pathology and audiology. In addition to the affiliations with Harvard University, joint training and research programs have been established with Boston College, Boston University, Brandeis University, Emerson College, the Massachusetts Institute of Technology, Simmons College and Tufts University.

Service programs are being carried out in close cooperation with the recently developed Statewide plan. Emphasis has been on the development of community resources, particularly those which offer alternative patterns of care to residential placement for the mildly and moderatly retarded, and the provision of a therapeutic residential environment which will encourage the emotional, social and intellectual development of the profoundly and severely retarded.

Total Cost:	$2,219,300
Federal Share:	724,725
Date of Award:	April 1965
Completion Dates:	University-Affiliated Center - April 1967 Research Center - November 1967



Eunice Kennedy Shriver Center, Waltham, Massachusetts

12. NEW YORK MEDICAL COLLEGE
NEW YORK, NEW YORK

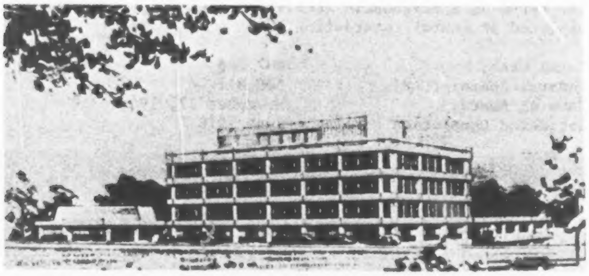
The University-Affiliated Facility is an integral part of the New York Medical College complex. The Medical College has operated a retardation Center since 1950 and has an ongoing inter-disciplinary approach to training, service, and research in the field. The University-Affiliated Facility will allow an additional 500 persons to be accepted for evaluation and service annually. A 20-bed inpatient wing will provide intensive diagnostic, treatment, and training resources, and opportunity for observation of family-patient inter-action.

New York Medical College will improve the clinical competence of its training programs, by utilizing the Facility to provide a focal point for the diagnosis, care, treatment and rehabilitation of the retarded. With the additional facilities, it is expected that the Facility will accept 500 additional patients annually for evaluation and service. An inpatient wing of the proposed Facility will provide 23 beds for intensive diagnosis, treatment, services and training. Children from infancy through adolescence will be admitted; however, the Facility will serve patients at all levels of retardation--profound, severe, moderate, mild and border line.

The Administrative Director of the Facility is appointed by the Dean of the Medical School. The Director is responsible for the coordination of training from the affiliated universities: Columbia University, Fordham University, New York University.

Training programs will be conducted in pediatrics, psychology, neurology, psychiatry, social work, speech, nutrition, nursing, vocational rehabilitation, special education, physical and occupational therapy, dance, music and art therapy. The Training Program in mental retardation will include all levels of retardation. A variety of individuals, from profoundly to mildly retarded, with associated handicaps, will be represented in the clinical population. Provision is made for re-evaluation, longitudinal studies and management.

Total Cost: $4,000,000
Federal Share: 3,000,000
Date of Award: December 1965
Estimated Completion Date: June 1970



New York Medical College, New York

13. UNIVERSITY OF NORTH CAROLINA
CHAPEL HILL, NORTH CAROLINA

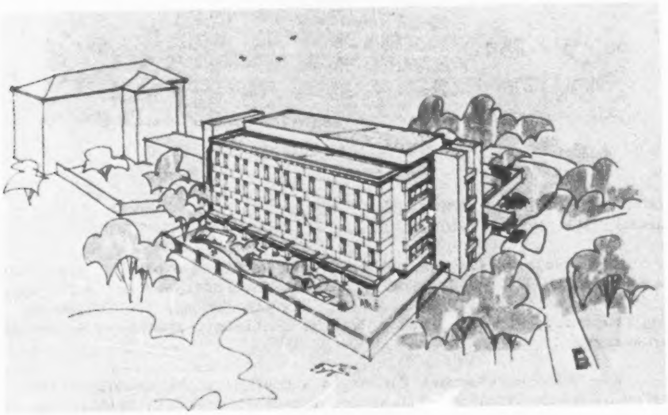
The Developmental Evaluation Clinic which is a part of the Child Development Center will be located within the University of North Carolina School of Medicine complex. Included in this complex are the following Training Programs: Nursing, Public Health, Dentistry, Pharmacy, Education, and Psychology.

The Child Development Center is situated in the middle of the University of North Carolina Medical complex which operates within the University administrative structure as a portion of the Division of Health Affairs. An Advisory Training Committee to the Child Development Center is responsible for the development, evaluation and the design of specialized Training Programs. The members of the committee represent the various schools and colleges of the total University structure and report to the appropriate deans.

The primary function of the Clinic will be the training of professional and specialized personnel in the diagnosis, treatment and management of retarded children. Other major responsibilities will include working with practicing physicians and state-supported clinics throughout the state, and problem patients from these sources will be accepted and returned to the community after a comprehensive work-up. The Clinic will be responsible to the program director of the Child Development Center and to the advisory committee for policies and programs. It will consist of two related units: (1) the outpatient facility for intensive evaluation, and (2) a day care facility for retarded children. The outpatient facility will be staffed by a multidisciplinary team to evaluate deviations from normal development and the establishment of treatment programs for the retardates and their families. Longitudinal follow-up will be a part of the clinic operations. The day care center will be utilized as part of the treatment program and will likewise involve a wide variety of necessary disciplines.

Approximately 150 new retarded patients will be seen and evaluated annually and a follow-up system will be instituted to cover a minimum period of 5 years and return visits will eventually increase from 1,000 to 1,200 annually. Twenty children will be enrolled in the day care unit. The day-care facility will serve as a diagnostic facility for prolonged observation of children suspected of mental retardation.

Total Cost:	$667,748
Federal Share: (UAF)	500,811
Date of Award:	November 17, 1966
Estimated Completion Date:	June 1970



University of North Carolina, Chapel Hill, North Carolina

14. THE OHIO STATE UNIVERSITY, COLUMBUS, OHIO

This University-Affiliated Facility will provide programs in twenty-six areas concerned with prevention and problem solving in mental retardation. The Facility will also contain programs to train child care aides, home instructors, developmental and remedial physical educators, and will conduct a wide range of tutorial seminars and training sessions for currently active professional and non-degree candidates.

Coordination with the State mental retardation plan for Ohio insures that the program will meet the realistic needs of the community and the region. The training and planning has been interwoven with the community needs and is based upon interdisciplinary evaluations, management, and long-term planning. Training programs will be coordinated through a training committee which represents the appropriate schools and colleges, all of which are on the same campus.

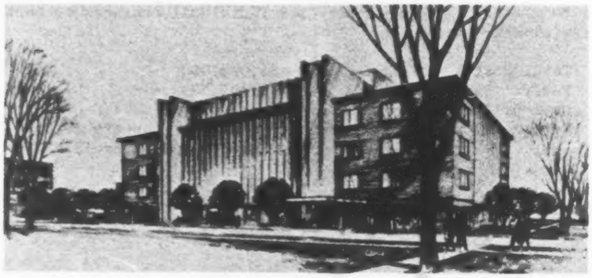
The various colleges within the University have been quick to grasp the opportunities which the Facility training program provides: extension of the breadth of current training programs and introduction of significant areas of research for more effective prevention and limitation of the impact of mental retardation on the child.

Referral of children and their families, or young adults will be made by health, educational, or social agencies as represented by the family physician, the public health nurse, the school principal, a special class teacher, the county welfare agency or a professional person with a voluntary health agency. The children to be seen will range from the mildly to the profoundly retarded. The age range is expected to be 0-21 years, however, older persons may be considered for assessment.

From the ambulatory or outpatient evaluations area, arrangements can be made to admit a patient to one of the 22 inpatient beds for further studies. Other indications for admission will be the occurrence of acute illness, children who are being cared for but cannot be managed at home, and social crisis of short duration in the family.

Complementing the inpatient and outpatient services as an integral part of the Facility operation is a Family Evaluation Unit made up of six motel-like facilities which will enable the family of the retardate to stay for the short time necessary for evaluation. There will also be an adolescent unit made up of 28 beds (14 for boys, 14 for girls), concerned primarily with preparing previously institutionalized retardates in their teens and late teen for return to the community.

Total Cost:	$4,950,000
Federal Share:	3,600,000
Date of Award:	January 1969
Estimated Completion Date:	July 1971



Ohio State University, Columbus, Ohio

15. UNIVERSITY OF OREGON, PORTLAND AND EUGENE, OREGON

The Center will consist of two Facilities, one in Portland on the Medical School campus and one in Eugene on the University of Oregon campus. Both units will become the components of an ongoing professional training and demonstration program. The proposed inter-campus Center plan is predicated on the successful experience in a similar program in speech pathology and on 18 months experience with an ongoing pilot project in mental retardation being carried on at both campuses.

The Crippled Children's Division of the Medical School will implement the policy of the University-Affiliated Facility and the Oregon School of Education at Eugene will plan and execute the curriculum and course work for joint training of special education personnel in mental retardation and handicapping conditions.

The School of Social Work at Portland State College and the State Department of Special Education will participate in the training program to meet the training needs of the State. A physician with specialized training in the field of pediatrics will be assigned by the Medical School to the Eugene facility to be responsible for the medical and biological aspects of the teaching program on the University campus.

The Center will make it possible to coordinate and expand the present clinical services provided for the mentally retarded. The Center will have as its objectives: the further development of ongoing training programs; the expansion of the Mental Retardation Laboratory Clinic; the development and enrichment of curriculum development; the provision of an adequate number of specialized personnel needed within the communities of the State for the mentally retarded; the introduction of the interdisciplinary team concept for exemplary patient care; the training of graduate and post-graduate students in the biomedical and behavioral sciences; development of short-term courses and institutes for practitioners in medicine, dentistry, and allied health personnel to enhance the opportunity for individual trainees to benefit in a multidisciplinary setting.

Total Cost:	$5,072,000
Federal Share:	3,706,500
Date of Award:	August 1966
Estimated Completion Date:	Portland: January 1970 Eugene: December 1970

University of Oregon, Eugene Oregon

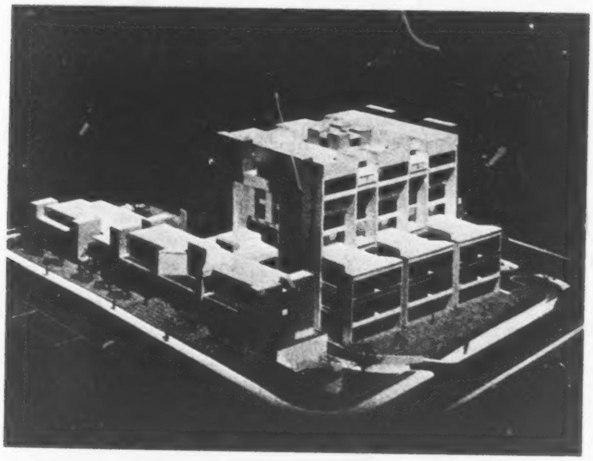
16. UNIVERSITY OF TENNESSEE, MEMPHIS, TENNESSEE

The University-Affiliated Facility, known as the University of Tennessee Child Development Center, is part of the University of Tennessee Medical Center, and, like its parent organization, serves the mid south area. The Child Development Center provides direct services to the mentally retarded, functions as an information and referral agency, and also serves as a clinical training facility for students enrolled in several mid-south universities and colleges. A large percentage of the patient population is in the lowest socio-economic group which constitutes the high-risk segment of the mentally retarded population within the state. The staff of the Center has been active in the Memphis area in developing special education classes in public schools for the educable and the trainable, the development of a day care program for the severely retarded, the development of a preschool program for the mildly and the moderately retarded, the development of sheltered workshops, and the development of special classes for children with visual-perceptual motor handicaps.

Training is offered in several medical specialities, dentistry, nursing, speech pathology and audiology, psychology, nutrition, social work, special education, rehabilitation counselling, occupational therapy, and physical therapy. Training efforts are directed at both graduate and undergraduate levels. In addition to inpatient and outpatient service programs and special education classes, a day care program and a preschool program are planned.

The Center will provide improved services and education in the special education classes and teachers from Memphis State University in the training program will receive a practicum experience by observation of the retarded child from the diagnostic and evaluative process through the classroom experience. The inpatient facilities will permit more intensive studies of patients and increase the training and research potential. Closed circuit television and one-way viewing windows in observation rooms will be utilized to observe the inter-disciplinary approach in combating retardation.

Total Cost:	$4,266,280
Federal Share:	3,199,710
Date of Award:	March 1966
Estimated Completion Date:	January 1970



University of Tennessee, Memphis, Tennessee

17. UTAH STATE UNIVERSITY, LOGAN, UTAH

This University-Affiliated Facility will be located on the Logan campus adjacent to the north wing of the Edith Bowen Laboratories School. The Departments of Special Education, Psychology, Social Work, Audiology-Speech Pathology, Family Life and Child Development, Elementary Education and the Department of Health, Recreation and Physical Education will cooperate in using the facility for the training of professional personnel in the field of mental retardation.

Students from the Department of Special Education, Utah State University, and Idaho State University, will receive specialized training in educational diagnosis of retarded children that will be extended to master degree candidates in remedial reading and in mental retardation. Students in psychiatry at the College of Medicine at the University of Utah will participate in short-term internships established in cooperation with the Director of Child Psychiatric Services at the College of Medicine. Students in nursing training at Weber State College will participate in short-term internships for training in medical training required by retarded persons who receive comprehensive diagnosis and evaluation.

The administration of the Facility will be under the direction of the Dean of the College of Education who will be assisted by the Head of Department of Special Education. An advisory board will be established whose functions will consist of the development of long-term program plans for future expansion of the Facility; clarification of problems involving interagency communication; review of training proposals; and consultation in hiring of personnel.

Total Cost:	$911,406
Federal Share:	682,054
Date of Award:	February 1968
Estimated Completion Date:	January 1971

Utah State University, Logan, Utah

B. UNIVERSITY OF WISCONSIN, MADISON, WISCONSIN

The University of Wisconsin Center in Mental Retardation and the Related Aspects of Human Development will provide a unique opportunity for training professional personnel in a multi-disciplinary approach to in-patient research and clinical services in the area of mental retardation. The Center is composed of a University-Affiliated Facility and a Research Facility funded under Title I, Part A of P.L. 88-164.

The Director of the Center is responsible to the Vice-President of the University. The Center Director has the responsibility for coordination of the many activities being carried on in the Center. He is responsible for coordination of : the Biomedical Services Research Unit; the School Rehabilitation Unit; the High Risk Population Laboratory; and the Central Wisconsin Colony Unit. He is also responsible for developing and monitoring the Center training programs.

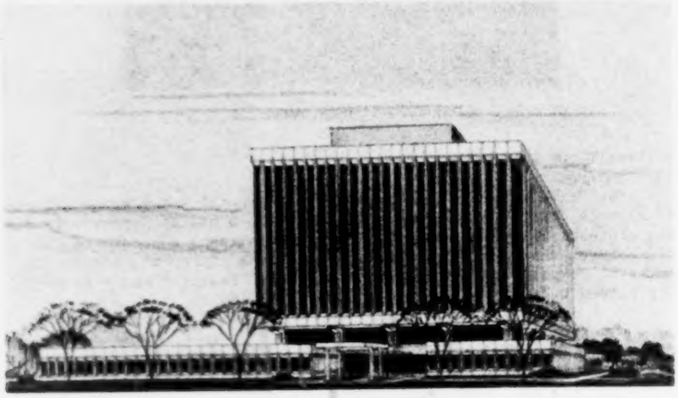
The programs to be conducted within the University-Affiliated Facility are structured so they will provide appropriate training in the research aspects of mental retardation as well as the training of professional personnel in the various disciplines considered necessary to provide a full range of services for the diagnosis and treatment, education, training, or care of the mentally retarded.

The Diagnostic and Treatment Outpatient Unit of the Facility will provide a full range of disciplines required in the comprehensive diagnosis of the mentally retarded, and it will serve as a major training resource for students in all fields represented and will provide a unique opportunity for interdisciplinary training.

The Central Wisconsin Colony Inpatient Unit of the Facility will be an integral resource because of its unique relationship with the University in providing training opportunities for faculty and students of the University of Wisconsin. (The units located at the Central Wisconsin Colony do not receive any federal construction support.)

The School Rehabilitation Unit of the Facility will have as its major objectives: the development and demonstration of new and improved techniques of education and rehabilitation; and the training of teachers and vocational rehabilitation personnel.

Total Cost:	$6,992,731
Federal Share UAF:	2,616,783
Federal Share Research:	2,263,000
Date of Award:	January 1969
Estimated Completion Date:	December 1971



University of Wisconsin, Madison, Wisconsin

ADDENDUM: MENTAL RETARDATION CHILD DEVELOPMENT CENTER, UNIVERSITY OF WASHINGTON, SEATTLE, WASHINGTON

The Mental Retardation Child Development Center is comprised of both a training and a research program which was funded in its entirety under Title I, Part A, of P.L. 88-164. (See Page2)

The training program offers comprehensive mental retardation child development training to medical students, pediatric residents, and post-doctoral fellows, speech and hearing trainees and fellows, nutrition trainees and fellows, psychology graduate students and interns, psychiatry residents and fellows, nursing undergraduates, pre- and post-masters students, and graduate social work students. In addition to the clinical research conducted in this setting, much effort is devoted to developing and maintaining extensive community/State relationships in both service and training.

The Behavioral Science Research Program in Psychology, Psychiatry, and Communications conducts clinical research program projects in this area which are closely integrated with other program units of the Center.

The Experimental Education Program provides a twelve classroom school facility for research and some multidisciplinary training in an educational setting in technological and behavioral aspects of teaching handicapped children. An estimated 150 students will be enrolled in this unit when in full operation.

A Residence Unit is designed to conduct training and research efforts in family interaction, and child-mother relations in a home environment. With television, audio and observation capabilities in each apartment unit, it provides significant expansion of total evaluation capabilities. Of the thirteen apartment units, one is for a resident manager, two for the Behavioral Science Research Program, and ten are related to the Clinical Training Unit.

Child Development and Mental Retardation Center, University of Washington, Seattle, Washington

University-Affiliated Facilities
Funded as of April 11, 1969

Institutions	Total Cost	Federal Share	Estimated/Completion Date
University of Alabama Birmingham and Tuscaloosa	$2,907,326	$2,180,494	Birmingham: January 1969 Tuscaloosa: October 1968
University of California Los Angeles, California	6,330,000	2,638,335	December 1968
University of Colorado Denver, Colorado	602,884	369,000	July 1968
Georgetown University Washington, D. C.	2,000,000	1,500,000	October 1969
University of Miami Miami, Florida	4,872,575	3,054,432	December 1970
Georgia Retardation Center Atlanta and Athens, Gerogia	Atlanta: 17,387,852	1,206,450	June 1969
	Athens: 2,137,248	1,887,713	June 1969
Indiana University Indianapolis and Bloomington, Indiana	4,277,635	3,157,231	Riley Hospital: January 1970 Bloomington: August 1969
University of Kansas Lawrence, Kansas City and Parsons, Kansas	3,860,000	2,729,400	December 1970
JFK Institute Baltimore, Maryland	3,147,000	2,360,250	November 1967
Children's Hospital Center Boston, Massachusetts	1,276,500	863,250	September 1967
Eunice Kennedy Shriver Center Waltham, Massachusetts	2,219,300	724,725	April 1967
New York Medical College New York, New York	4,000,000	3,000,000	January 1970
University of North Carolina Chapel Hill, North Carolina	Cost of Center for Disorders: 667,748	500,811	June 1970
Ohio State University Columbus, Ohio	4,950,000	3,600,000	July 1971
University of Oregon Portland and Eugene, Oregon	5,072,000	3,706,500	Portland: January 1970 Eugene: December 1970

Institutions	Total Cost	Federal Share	Estimated/Completion Date
University of Tennessee Memphis, Tennessee	$4,266,280	3,199,710	January 1970
Utah State University Logan, Utah	911,406	682,054	January 1971
University of Wisconsin Madison, Wisconsin	Total cost of Center: 6,992,731	2,616,783	December 1971
Total:	$73,423,485	$39,977,138	

COMMUNITY FACILITIES FOR THE MENTALLY RETARDED

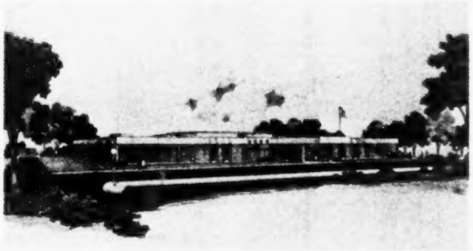
The Community Facilities Construction Program was authorized under Title I, Part C of the "Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963" (P.L. 88-164) and provides Federal grants to States to assist in the construction of specially designed public or other nonprofit facilities for the diagnosis, treatment, education, training, or personal care of the mentally retarded, including sheltered workshops which are part of facilities providing comprehensive services. A list of definitions describing both the facilities and the services is included on page 57. The program is administered at the State level by an officially designated State agency. Participation in the program requires the development of a State plan for the construction of community facilities for the mentally retarded based on an inventory of needed additional services and facilities. Construction projects are approved in accordance with the provisions of the State plan. Designated State agencies and allocations for construction of community facilities for the mentally retarded are shown on pages 58-63.

As of December 31, 1968, 242 projects had been approved for Federal assistance. The projects are classified by function; additional data are included in tabular form on pages 41-56.

The approved projects involve 223 facilities, several of which have received approval for more than one project. Of the 242 projects, 55 have been completed, 101 are under construction and 86 are in the initial approval stage. The total estimated cost is approximately $143.5 million and the estimated Federal share is $48.4 million. Upon completion the projects will provide services to more than 63,000 retardates of which 24,000 have not previously received services,and 39,000 will be provided improved and more extensive services.

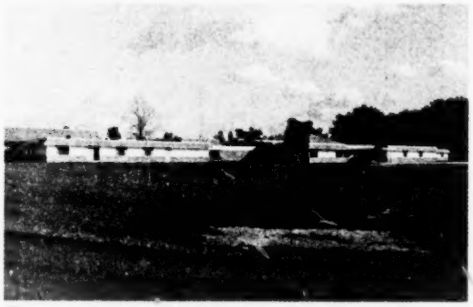
This construction program is administered by the Division of Mental Retardation, Rehabilitation Services Administration, Social and Rehabilitation Service, U. S. Department of Health, Education,and Welfare.

COMMUNITY FACILITIES FOR THE MENTALLY RETARDED



Blue Grass School for Retarded Children
Lexington, Kentucky

Las Trampas School, Lafayette, California



Marvin E. Beekman Center, Lansing, Michigan

FACILITIES APPROVED FOR FEDERAL ASSISTANCE UNDER THE MENTAL RETARDATION FACILITIES AND COMMUNITY MENTAL HEALTH CENTERS CONSTRUCTION ACT OF 1963

Title I, Part C, P.L. 88-164, as amended

(As of December 31, 1968)

STATE STATUS/NAME OF FACILITY*	LOCATION	OWN	TYPE OF FAC.	SERVICES AVAILABLE						RETARDED SERVED										ESTIMATED COST (IN THOUSANDS)	
										NUMBER			LEVELS OF RETARDATION				AGE GROUPINGS				
				D&E	TRT	EDU	TRG	PC	SWS	PRES.	ADD.	TOT.	MLD.	MOD.	SEV.	PROF	PRE-SCH.	SCH.	ADLT.	TOTAL	FEDERAL SHARE
	TOTALS	NP-116 P -107	D&E -7 Day -122 Res.-47 Day & Res.-66	168	169	190	213	223	84	39,128	23,991	63,119	72	206	96	122	148	217	163	$143,480	$48,396
ALABAMA																					
2 Opportunity Center School	Birmingham	NP	D	X	X	X	X	X		108	100	208		X	X		X	X		$ 436	$ 269
1 Lurleen B. Wallace Mental Retardation Hospital	Decatur	P	D&E	X				X		-0-	173	173	X	X	X	X	X	X	X	550	358
ALASKA																					
3. Harborview Memorial Hospital	Valdez	P	R	X	X	X	X	X	X	150	-0-	150			X	X		X	X	194	78
ARIZONA																					
3 Arizona Children's Colony	Coolidge	P	D,R	X	X	X	X	X	X	1,040	200	1,240	X	X	X	X	X	X	X	462	157
3 Valley of the Sun School for Retarded Children	Phoenix	NP	R		X	X	X	X		145	-0-	145	X	X	X	X	X	X	X	113	56
2 Perry Rehabilitation Center	Phoenix	NP	D	X	X	X	X	X	X	160	50	210	X	X			X	X	X	104	52
1 Tucson Mental Retardation Center	Tucson	P	D,R	X	X	X	X	X	X	-0-	243	243	X	X	X	X	X	X	X	958	100

STATE STATUS/NAME OF FACILITY	LOCATION	OWN	TYPE OF FAC.	SERVICES AVAILABLE D&E	TRT	EDU	TRG	PC	SWS	RETARDED SERVED NUMBER PRES.	ADD.	TOT.	LEVELS OF RETARDATION MLD.	MOD.	SEV.	PROF.	AGE GROUPINGS PRE-SCH.	SCH.	ADLT.	ESTIMATED COST (IN THOUSANDS) TOTAL	FEDERAL SHARE
ARKANSAS																					
1 Saline County Mental Retardation Day Care Center	Benton	NP	D			X	X	X		-0-	25	25	X	X	X			X	X	54	35
2 Arkansas Children's Colony	Conway	P	R	X	X	X	X	X		740	40	780	X	X	X	X	X	X	X	181	116
1 Union County Association for Retarded Children	El Dorado	NP	D	X	X	X	X	X	X	-0-	75	75		X	X	X	X	X	X	117	76
2 Bost School for Limited Children	Fort Smith	NP	D			X	X	X		33	30	63		X	X	X	X	X		229	152
2 Jenkin's Memorial Children's Center	Pine Bluff	NP	D	X	X	X	X	X	X	68	52	120	X	X	X	X	X	X		336	215
CALIFORNIA																					
3 Las Trampas School	Lafayette	NP	D,R			X	X	X		30	50	80	X	X	X		X	X	X	768	231
3 The Home of Guiding Hands	Lakeside	NP	R	X	X	X	X	X		-0-	192	192	X	X	X	X	X	X	X	2,077	626
3 Spastic Children's Foundation	Los Angeles	NP	D,R	X	X	X	X	X		85	85	170	X	X	X	X	X	X	X	757	249
3 Dubnoff School for Educational Therapy	North Hollywood	NP	D			X	X	X		48	36	84	X	X			X	X		365	115
3 Salem Christian School for the Handicapped	Ontario	NP	D,R				X	X		24	48	72	X	X	X		X	X	X	620	180
2 Community Center for Retarded Children and Adults	Palo Alto	NP	D,R		X		X	X		70	160	230	X	X	X	X	X	X	X	358	111
2 Children's Hospital Child Development Clinic	San Diego	NP	D&E	X			X			50	250	300	X	X	X	X	X	X	X	1,336	143
1 Recreation Center for the Handicapped	San Francisco	NP	D				X	X		120	80	200	X	X	X	X	X	X	X	521	174
2 Mental Retardation Services for Santa Clara County	San Jose	P	D	X	X	X	X	X	X	94	106	200	X	X	X	X	X	X	X	1,137	359
1 Harbor Area Retarded Children's Foundation	San Pedro	NP	D	X	X	X	X	X	X	40	60	100	X	X	X	X	X	X	X	430	138
3 St. Vincent's School	Santa Barbara	NP	D		X	X	X	X		155	25	180	X	X	X	X		X		457	149
3 Youth Activity Center	Stockton	NP	D	X	X	X	X	X	X	36	44	80	X	X				X	X	94	31
2 Good Shepherd Lutheran Home of the West	Terra Bella	NP	R	X	X	X	X	X	X	154	120	274	X	X	X	X	X	X	X	1,184	305

STATE STATUS/NAME OF FACILITY	LOCATION	OWN	TYPE OF FAC.	SERVICES AVAILABLE						RETARDED SERVED										ESTIMATED COST (IN THOUSANDS)	
										NUMBER			LEVELS OF RETARDATION				AGE GROUPINGS				
				D&E	TRT	EDU	TRG	PC	SWS	PRES.	ADD.	TOT.	MLD.	MOD.	SEV.	PROF.	PRE-SCH.	SCH.	ADLT.	TOTAL	FEDERAL SHARE
COLORADO																					
1 Mental Health & Mental Retardation Center	Boulder	NP	D	X	X	X	X	X	X	61	61	122	X	X	X	X	X	X	X	$ 446	$ 91
2 Robin Rogers School	Cortez	NP	D	X		X		X		7	2	9			X		X	X		36	16
3 Laradon Hall School for Exceptional Children 1/	Denver	NP	D,R	X	X	X	X	X	X	191	83	274	X	X	X		X	X	X	439	191
2 Residential & Training Facility for Retarded Children	Julesburg	NP	D,R		X	X	X	X		16	19	35		X				X		98	43
1 State Home & Training School	Wheat Ridge	P	R	X	X	X	X	X	X	1,050	-0-	1,050	X	X	X	X	X	X	X	100	45
CONNECTICUT																					
1 Mansfield State Training School	Mansfield Depot	P	D,R	X	X	X	X	X	X	1,650	304	1,954	X	X	X	X	X	X	X	800	166
2 New Haven Regional Center for the Mentally Retarded	New Haven	P	D,R	X	X	X	X	X	X	46	30	76	X	X	X	X	X	X		235	50
2 Hartford Regional Center for the Mentally Retarded	Newington	P	D,R	X	X	X	X	X	X	66	26	92	X	X	X	X		X		235	50
2 Putnam Regional Center for the Mentally Retarded	Putnam	P	D	X	X	X	X	X		93	110	203	X	X	X	X	X	X	X	868	65
3 Seaside Regional Center 2/	Waterford	P	D,R	X	X	X	X	X	X	235	56	291	X	X	X	X	X	X	X	484	67
DELAWARE																					
3 Hospital for the Mentally Retarded	Georgetown	P	D,R	X	X	X	X	X		480	-0-	480	X	X	X		X	X	X	1,601	300
DISTRICT OF COLUMBIA																					
1 Area "B" Comprehensive Health Center	Wash., D.C.	P	D,R	X	X	X	X	X	X	-0-	300	300	X	X	X		X	X	X	917	300

STATE STATUS/NAME OF FACILITY	LOCATION	OWN	TYPE OF FAC.	SERVICES AVAILABLE						RETARDED SERVED											ESTIMATEL COST (IN THOUSANDS)	
										NUMBER			LEVELS OF RETARDATION				AGE GROUPINGS					
				D&D	TRT	EDU·	TRG	PC	SWS	PRES.	ADD.	TOT.	MLD.	MOD.	SEV.	PRC	PRE-SCH.	SCH.	ADLT.	TOTAL	FEDERAL SHARE
FLORIDA																					
2 Brevard Training Center School	Eau Gallie	NP	D	X	X	X	X	X	X	31	14	45		X	X		X	X	X	$ 111	$ 55
1 Sunland Training Center at Gainesville	Gainesville	P	D,R			X	X	X		60	-0-	60		X	X				X	140	70
3 Morning Star School at Jacksonville	Jacksonville	NP	D		X	X	X	X		39	30	69	X	X	X		X	X		126	63
2 Palm Beach Habilitation Center	Lake Worth	NP	D,R	X	X	X	X	X	X	79	45	124	X	X	X	X		X	X	300	130
3 Sunland Training Center at Miami	Miami	P	D,R	X	X	X	X	X	X	340	1,160	1,500	X	X	X	X	X	X	X	4,349	326
2 Open Door School	New Port Richey	NP	D			X	X	X		10	10	20		X			X	X		45	22
2 Marian Center for Exceptional Children	Opa Locka	NP	D	X	X	X	X	X		67	96	163	X	X	X	X	X	X		422	211
1 Morning Star School at Orlando	Orlando	NP	D		X	X	X	X		26	14	40	X	X	X				X	99	50
1 Morning Star School at Pinellas Park	Pinellas Park	NP	D		X	X	X	X		-0-	43	43	X	X	X		X	X		123	62
1 Regional Community Center	St.Petersburg	P	D,R	X	X	X	X	X	X	-0-	300	300		X	X		X	X	X	500	250
2 MacDonaldSpeech and Hearing Clinic	Tampa	NP	D	X	X			X		198	110	308	X	X	X	X	X	X	X	63	31
GEORGIA																					
2 Georgia Retardation Center	Doraville	P	D&E	X				X		-0-	200	200	X	X	X	X	X	X	X	1,847	923
HAWAII																					
3 Ho'opono Annex (Lanakila Crafts)	Honolulu	P	D	X	X	X	X	X	X	65	130	195	X	X				X	X	255	100
2 Waimano Training School and Hospital	Honolulu	P	R	X	X	X	X	X	X	83	6	89	X	X				X	X	1,188	200
1 Brantley Center	Honokaa	P	D	X	X	X	X	X	X	10	20	30	X	X				X	X	176	81
IDAHO																					
2 Mental Retardation Child Development Center	Idaho Falls	P	D	X	X	X	X	X		8	39	47		X	X		X	X		188	110

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										NUMBER			LEVELS OF RETARDATION				AGE GROUPINGS				
				D&E	TRT	EDU	TRG	PC	SWS	PRES.	ADD.	TOT.	MLD.	MOD.	SEV.	PROF	PRE-SCH	SCH.	ADLT.	TOTAL	FEDERAL SHARE
IDAHO (cont.)																					
1 Mental Retardation Child Development Center	Lewiston	P	D	X	X	X	X	X		38	10	48	X	X	X			X	X	$ 168	$ 97
3 Idaho State School and Hospital [3]	Nampa	P	D,R	X	X	X	X	X	X	773	-0-	773	X	X	X	X	X	X	X	547	322
1 Mental Retardation Child Development Center	Twin Falls	P	D	X	X	X	X	X		5	40	45		X	X		X	X		174	105
ILLINOIS																					
1 Mamie O. Stookey School for Retarded Children	Belleville	NP	D	X	X	X	X	X	X	21	19	40	X	X	X	X	X	X	X	334	214
1 St. Mary of Providence School	Chicago	NP	D,R	X	X	X	X	X	X	294	13	307	X	X	X		X	X	X	692	360
2 Progress School	Decatur	P	D	X	X	X	X	X	X	64	106	170	X	X	X	X	X	X	X	642	391
3 Warren Achievement School for Handicapped Children	Monmouth	NP	D	X	X	X	X	X		30	40	70	X	X	X	X	X	X	X	293	106
2 Park Lawn School & Activity Center	Oak Lawn	NP	D	X	X	X	X	X		41	23	64		X	X	X	X	X		517	200
2 Little City Facility for the Mentally Retarded	Palatine	NP	D,R	X	X	X	X	X	X	89	50	139	X	X	X	X		X	X	655	237
1 Residential Home for Peoria Association for Retarded Children	Peoria	NP	R	X	X	X	X	X	X	-0-	50	50		X	X			X	X	594	312
3 Clearbrook Center for the Retarded	Rolling Meadows	NP	D	X	X	X	X	X	X	64	80	144	X	X	X	X	X	X	X	168	65
3 Hope School for Blind Multiple Handicapped Children [4]	Springfield	NP	R	X	X	X	X	X		28	36	64	X	X	X			X		698	375
2 Happiday Work Center	Steger	NP	D	X	X	X	X	X	X	20	70	90	X	X	X			X	X	47	26
1 Opportunity School for the Mentally Handi-capped	Moline	NP	D	X	X	X	X	X	X	64	86	150	X	X	X		X	X	X	579	349
INDIANA																					
2 Lake County Association for Retarded Children Sheltered Workshop & Training Center	Gary	NP	D	X	X	X	X	X	X	90	110	200	X	X	X	X		X	X	503	238

STATE STATUS/NAME OF FACILITY	LOCATION	OWN	TYPE OF FAC	SERVICES AVAILABLE						RETARDED SERVED										ESTIMATED COST (IN THOUSANDS)	
										NUMBER			LEVELS OF RETARDATION				AGE GROUPINGS				
				D&E	TRT	EDU	TRG	PC	SWS	PRES.	ADD.	TOTAL	MLD.	MOD.	SEV.	PROF	PRE-SCH.	SCH.	ADLT.	TOTAL	FEDERAL SHARE
INDIANA (cont.)																					
3 Wabash Center for the Mentally Retarded	Lafayette	NP	D	X	X	X	X	X	X	65	55	120	X	X	X		X	X	X	561	$ 239
2 Hendricks Habilitation Center	Logansport	NP	D	X	X	X	X	X	X	22	28	50	X	X	X			X	X	58	47
3 Green Acres	Richmond	NP	D	X	X	X	X	X	X	64	89	153	X	X	X	X	X	X	X	417	198
2 St. Joseph County Mental Retardation Center	South Bend	NP	D	X	X	X	X	X	X	63	138	201	X	X	X	X	X	X	X	1,595	746
IOWA																					
1 Sout[illegible]ast Iowa Area De[illegible]lopment Center	Burlington	NP	D,R	X	X	X	X	X	X	65	70	135		X	X			X	X	350	175
2 Black Hawk Development Center	Waterloo	NP	D	X	X	X	X	X		182	174	356	X	X	X	X	X	X	X	932	423
1 Pleasant Hill School	Marshalltown	P	D	X	X	X	X	X	X	40	30	70		X	X	X		X		315	169
KANSAS																					
2 Lakemary Center	Paola	NP	D,R	X	X	X	X	X		-0-	79	79	X	X				X		1,345	[illegible]
1 Community Center for the Mentally Retarded	Topeka	NP	D				X	X		44	6	50	X	X	X	X	X	X	X	189	98
KENTUCKY																					
1 Riverside-Good Counsel Mental Retardation Center	Covington	NP	D	X	X	X	X	X		163	47	210	X	X			X	X		880	500
2 Blue Grass School for Retarded Children	Lexington	P	D	X	X	X	X	X		80	60	140		X	X		X	X		571	210
3 Sheltered Workshop & Occupational Training Center	Louisville	NP	D	X	X	X	X	X	X	39	128	167	X	X	X			X	X	335	209
2 J.U. Kevil Mental Retardation Center	Mayfield	NP	D	X	X	X	X	X		-0-	50	50		X	X		X	X	X	419	191
1 Owensboro Council for Retarded Children Diagnostic & Evaluation Clinic	Owensboro	NP	D	X	X	X	X	X		78	71	149	X	X	X		X	X	X	94	[illegible]

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				D&E	TRT	EDU	TRG	PC	SWS	PRES.	ADD.	TOTAL	MLD.	MOD.	SEV.	PROF	PRE-SCH.	SCH.	ADLT.	TOTAL	FEDERAL SHARE
LOUISIANA																					
1 Columbia State School	Columbia	P	R	X	X		X	X		-0-	48	48			X	X	X	X	X	$ 333	$ 200
1 Pinecrest State School	Pineville	P	R	X	X		X	X		39	-0-	39				X		X	X	42	25
2 Ruston State School 5/	Ruston	P	R	X	X	X	X	X		150	42	192	X					X		1,11[illegible]	666
MAINE																					
1 Bangor Mental Retardation Facility	Bangor	P	R		X		X	X		-0-	82	82			X	X	X	X	X	674	324
2 Katahdin Friends of Exceptional Children	E.Millinocket	NP	D				X	X		15	-0-	15	X	X	X	X		X	X	138	80
3 Opportunity Training Center	Presque Isle	NP	D				X	X		38	32	70	X	X	X			X	X	230	133
3 Hilitop School	Waterville	NP	D			X	X	X		20	30	50	X	X	X			X		113	65
MARYLAND																					
1 Chimes Resident Home	Baltimore	NP	D,R			X	X	X		106	32	138		X	X			X	X	270	122
1 Harford County Residential Home & Day Care Center	Bel Air	NP	D,R	X	X	X	X	X	X	45	50	95	X	X	X	X	X	X	X	496	225
2 Metropolitan Washington Center for the Mentally Retarded	Beltsville	P	D,R	X	X	X	X	X		-0-	230	230	X	X	X	X	X	X	X	4,151	323
1 Regional Health & Mental Health Center	Cumberland	P	D&E	X				X		315	38	353	X	X			X	X	X	1,672	16
MASSACHUSETTS																					
1 Mental Health-Mental Retardation Treatment, Training & Research Center	Boston	P	D,R	X	X	X	X	X		30	205	235	X	X	X		X	X	X	1,498	334
2 Community Agencies Building	Concord	NP	D	X	X	X	X	X	X	47	47	94		X	X	X	X	X	X	153	54
2 Hathorne State School 6/ for Mentally Retarded	Danvers	P	D,R	X	X	X	X	X	X	205	132	337	X	X	X	X	X	X	X	2,195	424

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MICHIGAN																					
2 Clare-Gladwin Day Center	Clare	P	D	X	X	X	X	X		19	25	44		X	X		X	X		$ 239	$ 124
3 Marvin E. Beekman Center (Lansing Evaluation & Training Center)	Lansing	P	D	X	X	X	X	X	X	69	199	268		X	X	X	X	X	X	1,486	619
2 Western Michigan Mental Retardation Center	Muskegon	P	D,R	X	X	X	X	X		-0-	650	650	X	X	X	X	X	X	X	4,833	656
MINNESOTA																					
3 Lake Park-Wild Rice Children's Home	Fergus Falls	NP	R	X	X	X	X	X		25	15	40	X					X		432	216
3 Louise Whitbeck Fraser School	Richfield	NP	D			X	X	X		60	40	100		X	X	X	X	X	X	305	141
1 Child Development Center	St. Paul	P	D	X	X	X	X	X		290	110	400		X	X			X		1,952	701
2 Mt. Olivet Rolling Acres	Victoria	NP	R				X	X		16	32	48		X	X			X		965	361
3 Hammer School	Wayzata	NP	R			X	X	X		42	16	58	X	X	X			X	X	209	102
MISSISSIPPI																					
1 Regional Evaluation & Training Center	Tupelo	P	R	X	X	X	X	X	X	251	216	467	X	X	X	X	X	X	X	283	189
MISSOURI																					
2 Hannibal Regional Diagnostic Clinic for Mental Retardation	Hannibal	P	D,R	X	X	X	X	X		-0-	80	80	X	X	X	X	X	X	X	495	214
1 Kansas City Regional Diagnostic Clinic for Mental Retardation	Kansas City	P	D,R	X	X	X	X	X		-0-	300	300	X	X	X	X	X	X	X	797	392
2 Kirksville Regional Diagnostic Clinic for Mental Retardation	Kirksville	P	D,R	X	X	X	X	X		-0-	80	80	X	X	X	X	X	X	X	467	213
2 Sikeston Regional Diagnostic Clinic for Mental Retardation	Sikeston	P	D,R	X	X	X	X	X		-0-	80	80	X	X	X	X	X	X	X	502	211

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				D&E	TRT.	EDU	TRG	PC	SWS	PRES.	ADD.	TOT.	MLD.	MOD.	SEV.	PROF.	PRE-SCH.	SCH.	ADLT.	TOTAL	FEDERAL SHARE
MONTANA																					
2 Boulder River School & Hospital 1/	Boulder	P	R	X	X	X	X	X		30	219	249	X	X	X	X	X	X	X	$ 2,030	$ 539
2 Eastern Montana Facility for the Mentally Retarded	Glendive	P	D,R	X	X	X	X	X	X	-0-	46	46	X	X				X		347	183
NEVADA																					
1 Opportunity Center	Las Vegas	NP	D			X	X	X		34	66	100	X	X	X		X	X	X	216	74
1 Mentally Retarded Children's Cottages	Las Vegas	P	R	X	X	X	X	X	X	-0-	24	24	X	X	X			X		227	77
1 Washoe Association for Retarded Children Development Center	Reno	NP	D			X	X	X		17	36	53	X	X	X		X	X	X	146	50
1 Mentally Retarded Children's Cottages	Sparks	P	R	X	X	X	X	X	X	-0-	24	24	X	X	X			X		228	76
NEW HAMPSHIRE																					
3 Mary Hitchcock Memorial Hospital	Hanover	NP	D	X	X			X		253	585	838	X	X	X	X	X	X	X	235	117
3 Laconia State School	Laconia	P	R	X	X	X	X	X		976	100	1,076	X	X	X	X	X	X	X	381	191
NEW JERSEY																					
3 Camden County Day Care Center	Cherry Hill	P	D				X	X		5	75	80			X	X		X		434	153
2 Somerset County Day Care Center	Hillsborough	P	D				X	X		8	32	40			X	X		X		427	137
2 Warren County Day Care Center	Mansfield	P	D				X	X		13	27	40			X	X		X		392	139
2 Alhambra Pavilion Day Care Center	Newark	NP	D	X	X	X	X	X		30	90	120	X	X	X		X	X		535	194
2 Passaic County Day Care Center	Totowa	P	D				X	X		16	64	80			X	X		X		469	124
3 Mercer County Day Care Center	Trenton	P	D				X	X		16	64	80			X	X		X		529	124
2 Cumberland County Day Care Center	Vineland	P	D				X	X		8	40	48			X	X		X		352	124

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										NUMBER			LEVELS OF RETARDATION				AGE GROUPINGS				
				D&E	TRT	EDU	TRG	PC	SWS	PRES.	ADD.	TOTAL	MLD.	MOD.	SEV.	PROF.	PRE-SCH.	SCH.	ADLT.	TOTAL	FEDERAL SHARE
NEW MEXICO																					
2 Vista Larga Center	Albuquerque	P	D,R	X	X	X	X	X		-0-	250	250	X	X	X	X	X	X	X	$ 200	$ 100
2 Child Development Center of Lea County	Hobbs	NP	D	X	X	X	X	X		13	27	40	X	X	X	X	X	X	X	59	29
NEW YORK																					
2 Shield of David Institute for Retarded Children	Bayside	NP	D	X	X	X	X	X		-0-	250	250	X	X	X	X	X	X	X	1,080	200
1 Edenwald Center Residential Facility	Bronx	NP	R	X	X	X	X	X		40	32	72	X	X	X	X	X	X	X	1,275	425
2 Louis & Martha Silver Day Training Center	Brookville	NP	D	X	X	X	X	X	X	317	224	541		X	X	X	X	X	X	612	204
3 Maimonides School	Far Rockaway	NP	D,R	X	X	X	X	X	X	77	44	121	X	X				X		631	210
1 Vocational Training Center & Sheltered Workshop	Freeport	NP	D	X	X	X	X	X	X	-0-	500	500	X	X	X			X	X	1,586	203
2 Rockland County Community Mental Health Center	Pomona	P	D				X	X		10	60	70	X	X			X	X		210	57
2 Dutchess County Mental Health Center	Poughkeepsie	P	D	X	X	X	X	X	X	227	85	312	X	X	X	X	X	X	X	1,271	381
3 Monroe County Center for Rehabilitation Agencies	Rochester	NP	D	X	X	X	X	X	X	486	200	686	X	X	X	X	X	X	X	3,759	552
1 Nassau County Cerebral Palsy Treatment and Rehabilitation Center	Roosevelt	NP	D	X	X	X	X	X	X	199	-0-	199	X	X	X	X	X	X	X	308	36
1 Onondaga County Association for Retarded Children Activities Center	Syracuse	NP	D	X	X	X	X	X	X	122	98	220	X	X	X	X	X	X	X	900	300
2 Pinewoods Center for the Retarded (Rensselaer County Association for Retarded Children Training Center)	Troy	NP	D				X	X		42	49	91	X	X			X	X	X	126	40
3 Jefferson County Association for Retarded Children Training Center	Watertown	NP	D	X	X	X	X	X	X	20	59	79	X	X	X		X	X	X	283	79

STATE STATUS/NAME OF FACILITY	LOCATION	OWN	TYPE OF FAC	SERVICES AVAILABLE						RETARDED SERVED										ESTIMATED COST (IN THOUSANDS)	
										NUMBER			LEVELS OF RETARDATION				AGE GROUPINGS				
				D&E	TRT	EDU	TRC	PC	SWS	PRES.	ADD.	TOTAL	MLD.	MOD.	SEV.	PROF.	PRE-SCH.	SCH.	ADLT.	TOTAL	FEDERAL SHARE
NORTH CAROLINA																					
1 Irene Wortham Day Care Center	Asheville	NP	D		X	X	X	X		29	35	64	X	X	X		X	X		$ 213	$ 132
2 Facility for the Mentally Retarded	Butner	P	R	X	X	X	X	X		-0-	36	36	X	X				X		504	318
2 Western Carolina University Mental Health Center & Mental Retardation Facility	Cullowhee	P	D	X	X	X	X	X		208	222	430	X	X	X	X	X	X	X	323	168
2 Gaston Children's Center	Gastonia	P	D	X	X	X	X	X	X	-0-	60	60	X	X	X	X	X	X	X	385	236
2 East Carolina Sheltered Workshop & Vocational Rehabilitation Center	Greenville	NP	D	X	X	X	X	X	X	-0-	100	100	X	X	X			X	X	285	179
1 East Carolina University Developmental Evaluation Center	Greenville	P	D	X	X	X	X	X		234	92	326	X	X	X	X	X	X	X	239	148
NORTH DAKOTA																					
2 Neuropsychiatric Institute	Fargo	NP	D&E	X				X		-0-	180	180	X	X	X	X	X	X	X	365	216
OHIO																					
2 Lorain County School for Retarded Children	Carlisle Twnshp	P	D	X			X	X		355	121	476		X	X	X	X	X		1,683	318
3 Bessie Benner Metzenbaum Opportunity School	Chesterland	P	D			X	X	X		66	48	114		X	X	X	X	X	X	280	23
3 Resident Home for the Mentally Retarded of Hamilton County	Cincinnati	NP	D,R		X	X	X	X		-0-	50	50		X	X		X	X	X	212	73
1 Montgomery County Retarded Children's School	Dayton	P	D	X	X	X	X	X		318	200	518		X				X		2,066	397
2 Columbiana County School for Retarded (Robert Bycroft School)	Lisbon	P	D			X	X	X		97	23	120		X	X	X	X	X		400	107
3 Richland County School for the Mentally Retarded	Mansfield	P	D	X	X	X	X	X	X	163	146	309		X	X		X	X	X	478	116
1 Hattie Larlham Foundation	Mantua	NP	R	X	X			X		54	100	154			X	X	X			386	125

STATE			TYPE	SERVICES AVAILABLE						RETARDED SERVED										ESTIMATED COST (IN THOUSANDS)	
			OF							NUMBER			LEVELS OF RETARDATION				AGE GROUPINGS				
STATUS/NAME OF FACILITY	LOCATION	OWN	FAC.	D&E	TRT	EDU	TRG	PC	SMS	PRES.	ADD.	TOTAL	MLD.	MOD.	SEV.	PROF	PRE-SCH.	SCH.	ADLT.	TOTAL	FEDERAL SHARE
OHIO (cont.)																					
1 Sunnyside School for Retarded Children	Montpelier	P	D	X	X	X	X	X		14	22	36	X	X	X		X	X		$ 215	$ 64
2 Fairhaven School for Mentally Retarded Children	Niles	P	D			X	X	X		188	100	288	X	X	X		X	X		460	143
1 Happy Hearts School	Portsmouth	P	D	X	X		X	X		49	51	100		X	X		X	X	X	290	95
3 Mahoning County School for the Retarded	Youngstown	P	D	X	X	X	X	X	X	316	529	845		X	X	X	X	X	X	1,290	266
OKLAHOMA																					
1 Enid State School	Enid	P	R	X	X	X	X	X		996	-0-	996	X	X	X	X	X	X	X	382	191
1 Dale Rogers Center	Oklahoma City	NP	D		X	X	X	X		78	150	228	X	X	X		X	X	X	440	77
3 Pauls Valley State School [8]	Pauls Valley	P	R	X	X	X	X	X		700	-0-	700	X	X	X	X	X	X	X	671	336
1 Kay County Council Day Care Center	Ponca City	NP	D			X	X	X		21	29	50	X	X	X	X		X	X	147	73
OREGON																					
3 Pearl Buck School	Eugene	NP	D	X		X	X	X		55	45	100	X	X	X		X	X	X	237	118
1 Portland Children's Center	Portland	NP	D	X	X	X	X	X	X	95	40	135	X	X	X		X	X	X	165	83
1 Our Lady of Providence Child Center	Portland	NP	R		X		X	X		52	-0-	52	X	X	X		X	X		100	47
1 Haven School for Exceptional Children	Salem	NP	D			X	X	X		49	68	117	X	X	X		X	X	X	259	124
PENNSYLVANIA																					
2 Handi-Crafters, Inc.	Caln Township	NP	D	X	X	X	X	X	X	58	104	162	X	X	X			X	X	370	153
1 Elwyn Institute Day Care Center [9]	Elwyn	NP	D,R	X	X	X	X	X	X	29	127	156	X	X	X			X	X	825	196
2 Erie Center for Education & Training for the Mentally Retarded	Erie	NP	D,R	X	X	X	X	X	X	158	200	358	X	X	X	X	X	X	X	419	142
1 Camphill Special Schools	Glenmoore	NP	R	X	X	X	X	X		55	45	100	X	X				X		509	196
3 Clelian Heights School for Exceptional Children	Greensburg	NP	D,R	X	X	X	X	X		25	75	100	X	X				X		1,790	223

STATE STATUS/NAME OF FACILITY	LOCATION	OWN	TYPE OF FAC.	SERVICES AVAILABLE						RETARDED SERVED										ESTIMATED COST (IN THOUSANDS)	
										NUMBER			LEVELS OF RETARDATION				AGE GROUPINGS				
				D&D	TRT	EDU	TRG	PC	SWS	PRES.	ADD.	TOTAL	MLD.	MOD.	SEV.	PROF.	PRE-SCH.	SCH.	ADLT.	TOTAL	FEDERAL SHARE
PENNSYLVANIA (cont.)																					
3 Mercer County Sheltered Workshop	Hickory Twnship	NP	D	X	X	X	X	X	X	36	39	75	X	X	X				X	$ 370	$ 167
1 Bishop Sheltered Workshop	Jim Thorpe	NP	D	X	X	X	X	X	X	-0-	50	50	X	X	X	X			X	67	23
2 Lebanon County Workshop	Lebanon	NP	D	X	X	X	X	X	X	60	140	200	X	X	X				X	719	170
1 McGuire Memoria Developmental Skills Training Unit	New Brighton	NP	R	X	X	X	X	X		150	-0-	150		X	X	X	X	X		338	169
1 Children's Hospital of Philadelphia	Philadelphia	NP	D&E	X				X		998	500	1,498	X	X	X	X	X	X		2,406	174
3 Allied Services Community Residential Center for Mentally Retarded	Scranton	P	D,R	X	X	X	X	X	X	100	30	130	X	X	X	X	X	X	X	372	159
3 Sheltered Workshop of York County, Inc.	York	NP	D	X	X	X	X	X	X	90	74	164	X	X	X			X	X	361	107
PUERTO RICO																					
2 Psychopedagogic Institute	Bayamon	NP	D,R	X	X	X	X	X		123	64	187	X	X	X	X	X	X	X	681	512
1 University District Hospital Pediatric Department	Rio Piedras	P	D	X	X	X	X	X		-0-	75	75	X	X	X		X	X		1,580	655
RHODE ISLAND																					
3 Dr. Joseph H. Ladd School 10/	Exeter	P	R	X	X	X	X	X		834	-0-	834	X	X	X	X	X	X	X	709	354
3 J. Arthur Trudeau Memorial Center	Warwick	NP	D	X	X	X	X	X	X	3	97	100	X	X	X		X	X	X	152	35
SOUTH CAROLINA																					
2 South Carolina Retarded Children's Habilitation Center	Summerville	P	D,R	X	X	X	X	X	X	214	204	418	X	X	X	X	X	X	X	2,688	692

STATE STATUS/NAME OF FACILITY	LOCATION	OWN	TYPE OF FAC.	SERVICES AVAILABLE						RETARDED SERVED NUMBER			LEVELS OF RETARDATION				AGE GROUPINGS			ESTIMATED COST (IN THOUSANDS)	
				D&E	TRT	EDU	TRG	PC	SWS	PRES.	ADD.	TOTAL	MLD.	MOD.	SEV.	PROF.	PRE-SCH.	SCH.	ADLT.	TOTAL	FEDERAL SHARE
SOUTH DAKOTA																					
3 Adjustment Training Center	Sioux Falls	NP	D	X	X	X	X	X	X	42	60	102	X	X	X			X	X	$ 523	$ 300
TENNESSEE																					
2 Orange Grove Center for Retarded Children	Chattanooga	NP	D	X	X	X	X	X	X	500	500	1,000	X	X	X	X		X	X	2,118	614
2 Clover Bottom Hospital & School	Nashville	P	D	X	X	X	X	X	X	1,284	213	1,497	X	X	X	X	X	X	X	346	210
1 Training & Habilitation Center & Half-Way House	Nashville	NP	D,R	X	X	X	X	X	X	820	1,000	1,820		X	X	X	X	X	X	496	105
TEXAS																					
1 Abilene State School	Abilene	P	R		X	X	X	X		2,304	-0-	2,304		X	X	X	X	X	X	490	200
3 Amarillo State Center for Human Development	Amarillo	P	D	X	X	X	X	X		-0-	140	140	X	X	X		X	X	X	636	351
2 Austin State School Pre-Vocational Training Center	Austin	P	D,R	X	X	X	X	X	X	-0-	90	90	X	X	X			X		132	64
1 Community Training & Activity Center	Austin	NP	D	X	X	X	X	X		131	144	275	X	X	X	X	X	X	X	151	85
1 Travis State School	Austin	P	R			X	X	X		1,799	-0-	1,799	X	X	X	X		X	X	607	200
2 Baytown Opportunity Center for Mentally Retarded	Baytown	NP	D			X	X	X		40	43	83	X	X	X		X	X	X	130	73
2 Beaumont State Center for Human Development	Beaumont	P	D	X	X	X	X	X		-0-	140	140	X	X	X		X	X	X	697	382
2 Corpus Christi State School 11/	Corpus Christi	P	D,R.	X		X	X	X		-0-	661	661	X	X	X	X	X	X	X	2,138	1,198
2 Denton State School	Denton	P	D			X	X	X		-0-	120	120	X	X				X	X	150	76
1 South Texas Habilitation Center	Edinburg	P	D,R	X		X	X	X		105	245	350	X	X	X			X	X	675	378
1 Child Study Center	Forth Worth	NP	D	X	X	X	X	X		169	-0-	169	X	X	X		X	X	X	180	101
1 Sunshine Training Center	Galveston	NP	D			X	X	X		29	15	44		X	X			X	X	140	78
1 Marbridge House 12/	Houston	NP	R,D		X	X	X	X		32	45	77	X	X				X	X	314	176
2 Lubbock State School 13/	Lubbock	P	D,R	X		X	X	X		-0-	691	691	X	X	X	X	X	X	X	1,911	1,032
2 Lufkin State School 14/	Lufkin	P	D,R	X		X	X	X		695	288	983	X	X	X	X	X	X	X	2,717	1,441
2 Mexia State School	Mexia	P	R			X	X	X		1,600	-0-	1,600	X	X	X	X		X	X	597	287

STATE STATUS/NAME OF FACILITY	LOCATION	OWN	TYPE OF FAC.	SERVICES AVAILABLE						RETARDED SERVED NUMBER			LEVELS OF RETARDATION				AGE GROUPINGS			ESTIMATED COST (IN THOUSANDS)	
				D&E	TRT	EDU	TRG	PC	SMS	PRES.	ADD.	TOTAL	MLD.	MOD.	SEV.	PROF.	PRE-SCH.	SCH.	ADLT.	TOTAL	FEDERAL SHARE
TEXAS (cont.)																					
2 Thomas W. Hughen School for Crippled Children	Port Arthur	NP	D,R	X	X	X	X	X		44	5	49	X	X	X	X		X		$ 71	$ 40
UTAH																					
2 Utah Stat Training School	American Fork	P	R	X	X	X	X	X		950	28	978	X	X	X	X		X		295	115
2 Weber Training Center for the Handicapped	Ogden	P	D	X	X	X	X	X		150	150	300	X	X	X	X	X	X	X	1,503	751
2 Habilitation Center	Salt Lake City	P	D&E	X				X		3,485	-0-	3,485	X	X	X	X		X	X	88	44
1 Holladay Children's Center	Salt Lake City	NP	D,R	X	X	X	X	X		37	23	60	X	X	X	X	X	X		115	57
VERMONT																					
2 Brandon Training School[15/]	Brando	P	R	X	X	X	X	X	X	789	40	829	X	X	X	X	X	X	X	756	400
VIRGINIA																					
3 George Mason Center	Arlington	P	D	X		X	X	X		93	106	199	X	X	X	X	X	X	X	182	100
1 University of Virginia Children's Rehabilitation Center	Charlottesville	P	D,R	X	X	X	X	X		178	355	533	X	X	X		X	X	X	435	239
3 Joseph Willard Health Center	Fairfax	P	D	X	X	X	X	X		-0-	72	72	X	X	X	X	X	X	X	551	287
2 Woodrow Wilson Rehabilitation Center	Fisherville	P	R	X	X	X	X	X		410	-0-	410	X					X	X	537	283
1 Peninsula Association for Retarded Children	Hampton	NP	D	X	X	X	X	X	X	110	77	187	X	X	X	X	X	X	X	149	82
1 Zuni Presbyterian School	Zuni	NP	R			X	X	X		3	37	40	X	X	X			X	X	378	155
WASHINGTON																					
2 Fircrest Half-Way House	Seattle	P	R		X		X	X		-0-	56	56	X	X					X	642	267
1 Yakima Valley School	Selah	P	R	X	X	X	X	X		250	270	520		X	X	X	X	X	X	2,333	203

STATE STATUS/NAME OF FACILITY	LOCATION	OWN	TYPE OF FAC.	SERVICES AVAILABLE						RETARDED SERVED										ESTIMATED COST (IN THOUSANDS)	
										NUMBER			LEVEL OF RETARDATION				AGE GROUPINGS				
				D&E	TRT	EDU	TRG	PC	SWS	PRES.	ADD.	TOTAL	MLD.	MOD.	SEV.	PROF.	PRE-SCH.	SCH.	ADLT.	TOTAL	FEDERAL SHARE
WEST VIRGINIA																					
1 Region I Center for the Mentally Retarded	Institute	P	D			X	X	X		25	35	60		X	X	X	X	X		$ 305	$ 186
2 Green Acres	Le Sage	P	R			X	X	X		28	20	48	X	X				X	X	262	160
2 Roney's Point	Roney's Point	P	D				X	X		-0-	80	80			X			X		313	191
WISCONSIN																					
1 Walworth County Special School	Elkhorn	P	D	X	X	X	X	X		225	90	315	X	X	X			X		793	298
3 Community Service Center	Green Bay	NP	D	X	X	X	X	X	X	100	300	400	X	X	X	X	X	X	X	891	335
2 Kenosha Achievement Center	Kenosha	NP	D	X	X	X	X	X	X	27	33	60	X	X	X	X	X	X	X	263	101
WYOMING																					
2 School for Trainable Retarded Children & Work Training Center	Casper	P	D	X	X	X	X	X	X	70	98	168	X	X	X	X	X	X	X	436	211
1 Wyoming State Training School	Lander	P	R	X	X	X	X	X	X	-0-	94	94	X	X	X			X	X	200	100

*CODES OR ABBREVIATIONS

Status - (1) Initial Approval (2) Under Construction
(3) Completed

Ownership - OWN
Nonprofit - NP
Public -P

Type of Facility
Diagnostic and Evaluation Clinic - D&E
Day Facility - D
Residential Facility - R

Services Available
Diagnostic and Evaluation - D&E
Treatment - TRT
Education - EDU
Training - TRG
Personal Care - PC
Sheltered Workshop - SWS

Retarded Served
Number
Presently - PRES
Additional - ADD
Total - TOT
Levels of Retardation
Mild - MLD
Moderate - MOD
Severe - SEV
Profound - PROF
Age Groupings
Preschool - PRESCH
School - SCH
Adult - ADLT

Estimated Cost-In Thousands
Total Cost - TOTAL
Federal Share - FEDERAL SHARE

FOOTNOTES

(1) Two Projects - one completed; one in planning stage
(2) Two Projects - one completed; one under construction
(3) Two Projects - both completed
(4) Two Projects - one completed; one in planning stage
(5) Two Projects - both under construction
(6) Two Projects - both under construction
(7) Two Projects - one under construction; one in planning stage
(8) Two Projects - one completed; one in planning stage
(9) Two Projects - both in planning stage
(10) Two Projects - one completed; one in planning stage
(11) Three Projects - all under construction
(12) Three Projects - all in planning stage
(13) Three Projects - all under construction
(14) Three Projects - all under construction
(15) Two Projects - one under construction; one in planning stage

DEFINITIONS

I. Facilities:

A. D&E Clinic (Diagnostic and Evaluation Clinic): A facility providing diagnostic and evaluation services only.

B. Day Facility: A facility operating for care and treatment of the mentally retarded on less than 24 hour-a-day basis, providing diagnosis (and evaluation), treatment, education, training, personal care or sheltered workshop services.

C. Residential Facility: A facility operating for care and treatment of the mentally retarded on a 24 hour-a-day basis providing diagnosis (and evaluation), treatment, education, training, personal care, or sheltered workshop services.

II. Services:

A. Diagnosis and Evaluation: Coordinated medical, psychological, social service, educational, speech pathology, audiology, nursing,occupational therapy, physical therapy, nutrition, vocational and other related services carried out under the supervision of qualified personnel to assess the individual's abilities and disabilities, and family and community resources. Based on this assessment a plan to meet the needs of the individual and his family is developed and methods of implementation recommended. Periodic reassessment of the individual where needed is an essential aspect of this Service.

B. Treatment: Appropriate medical, dental, physical therapy, occupational therapy, hearing therapy, psychotherapy, social service and related services carried out under the direction of qualified personnel to bring about improvement in effective physical,psychological or social functioning of the mentally retarded individual.

C. Education: Services based on a structured curriculum of instruction carried out under supervision of teachers qualified in special education to meet the needs of the retarded in preschool, primary, intermediate, prevocational, vocational and other appropriate areas.

D. Training: Services carried out under the supervision of qualified personnel which provide for training of the retarded individual in motor skills, activities of daily living, vocational training, personality development, socialization, recreation and other related components.

E. Personal (custodial) Care: Services providing for the dietary, shelter, clothing, medical care, nursing and other daily personal needs of the retarded to insure proper personal care during the time the individual is utilizing the various other services offered by the facility.

F. Sheltered Workshop: Services carried out under the supervision of qualified personnel involving a program of paid work involving work evaluation, work adjustment training, occupational skill training, supervised transitional employment, placement and other related component services.

STATE AGENCIES RESPONSIBLE FOR COMMUNITY MENTAL RETARDATION FACILITIES CONSTRUCTION PROGRAM TITLE I, PART C, P.L. 88-164

ALABAMA: Ira L. Myers, M.D., State Health Officer, State Board of Health, Montgomery, Alabama 36104

ALASKA: J. Scott McDonald, Commissioner, Department of Health and Welfare, Alaska Office Building, Juneau, Alaska 99801

ARIZONA: George Spendlove, M.D., Commissioner of Public Health, State Department of Health, 1624 West Adams Street, Phoenix, Arizona 85007

ARKANSAS: J. T. Herron, M.D. State Health Officer, State Board of Health, Little Rock, Arkansas 72201

CALIFORNIA: Louis F. Saylor, M.D., Acting Director of Public Health, State Department of Public Health, Berkeley, California 94704

COLORADO: Roy L. Cleere, M.D., Director, State Department of Public Health, Denver, Colorado 80220

CONNECTICUT: Franklin M. Foote, M.D., Commissioner, State Department of Health, 79 Elm Street, Hartford, Connecticut 06115

DELAWARE: Floyd I. Hudson, M.D., Executive Secretary, State Board of Health, Dover, Delaware 19901

DISTRICT OF COLUMBIA: Murray Grant, M.D., Director, Department of Public Health, Washington, D.C. 20001

FLORIDA: James G. Foshee, Ph.D., Director, Division of Mental Retardation, Board of Commissioners of State Institutions, 908 South Bronough Street, Tallahassee, Florida 32304.

GEORGIA: John H. Venable, M.D., Director, Department of Public Health, 47 Trinity Avenue, S.W., Atlanta, Georgia 30334

GUAM: Joseph H. Gerber, Acting Director of Public Health and Social Services, Department of Public Health and Social Services, Agana, Guam 96910

HAWAII: Walter B. Quisenberry, M.D., Director of Health, Department of Health, Honolulu, Hawaii 96801

IDAHO: Terrell O. Carver, M.D., Administrator of Health, State Department of Health, Boise, Idaho 83701

ILLINOIS: Director, Department of Mental Health, Chicago, Illinois 60601

INDIANA: Andrew C. Offutt, M.D., State Health Commissioner, State Board of Health, Indianapolis, Indiana 46207

IOWA: James F. Speers, M.D., Commissioner of Public Health, State Department of Health, Des Moines, Iowa 50319

KANSAS: Robert A. Haines, M.D., Director, Division of Institutional Management, State Board of Social Welfare, Topeka, Kansas 66612

KENTUCKY: Russell E. Teague, M.D., Commissioner, State Department of Health, Frankfort, Kentucky 40601

LOUISIANA: E.L. Agerton, Director, State Department of Hospitals, 655 North 5th Street, Baton Rouge, Louisiana 70804

MAINE: Dean H. Fisher, M.D., Commissioner, Department of Health and Welfare, Augusta, Maine 04330

MARYLAND: William S. Spicer, M.D., Chairman, Board of Health and Mental Hygiene, Baltimore, Maryland 21201

MASSACHUSETTS: Milton Greenblatt, M.D., Commissioner, Department of Mental Health, 15 Ashburton Place, Boston, Mass. 02108

MICHIGAN R. G. Rice, M.D., Acting Director, Department of Public Health, Lansing, Michigan 48914

MINNESOTA: Morris Hursh, Commissioner, Department of Public Welfare, Centennial Building, St. Paul, Minnesota 55101

MISSISSIPPI: Dorothy N. Moore, Ph.D., Program Director, Interagency Commission on Mental Illness and Mental Retardation, Jackson, Mississippi 39205

MISSOURI: George A. Ulett, M.D., Director, Division of Mental Diseases, Department of Public Health and Welfare, Jefferson City, Missouri 65102

MONTANA: John S. Anderson, M.D., Executive Officer and Secretary, State Department of Health, Helena, Montana 59601

NEBRASKA: Lynn W. Thompson, M.D., Director, Department of Health, State Capitol Building, Lincoln, Nebraska 68509

NEVADA: Edward F. Crippen, M.D., State Health Officer, Division of Health, Department of Health, Welfare and Rehabilitation, Carson City, Nevada 89701

NEW HAMPSHIRE: Mary M. Atchison, M.D., M.P.H., Director, Division of Public Health, Department of Health and Welfare, 61 South Spring Street, Concord, New Hampshire 03301

NEW JERSEY: Lloyd W. McCorkle, Ph.D., Commissioner, Department of Institutions and Agencies, P.O. Box 1237, Trenton, New Jersey 08625

NEW MEXICO: John G. Jasper, Executive Director, Department of Public Health and Social Services, Santa Fe, New Mexico 87501

NEW YORK: Alan D. Miller, M.D., Commissioner, Department of Mental Hygiene, 119 Washington Avenue, Albany, New York 12225

NORTH CAROLINA: William F. Henderson, Executive Secretary, North Carolina Medical Care Commissioner, Raleigh, North Carolina 27601

NORTH DAKOTA: James R. Amos, M.D., State Health Officer, Department of Health, State Capitol, Bismarck, North Dakota 58501

OHIO: Martin A. Janis, Director, Department of Mental Hygiene and Correction, State Office Building, 65 South Front Street, Columbus, Ohio 43215

OKLAHOMA: Lloyd E. Rader, Director, Department of Public Welfare, Sequoyah Building, Box 531 61, Oklahoma City, Oklahoma 73105

OREGON: Kenneth D. Gaver, M.D., Administrator, Mental Health Division, State Board of Control, Salem, Oregon 97310

PENNSYLVANIA: Thomas W. Georges, M.D., Secretary, State Department of Public Welfare, Health and Welfare Building, Harrisburg, Pennsylvania 17120

PUERTO RICO: Manuel A. Torres-Aguiar, M.D., Secretary of Health, Department of Health, San Juan, Puerto Rico 00924

RHODE ISLAND: Joseph E. Cannon, M.D., Director of Health, Department of Health, State Office Building, Providence, Rhode Island 02903

SOUTH CAROLINA: E. Kenneth Aycock, M.D., State Health Officer, State Board of Health, Columbia, South Carolina 29201

SOUTH DAKOTA: G. J. Van Heuvelen, M.D., State Health Officer, State Department of Health, Pierre, South Dakota 57501

TENNESSEE: Nat T. Winston, Jr., M.D., Commissioner, Department of Mental Health, 300 Cordell Hull Building, Nashville, Tennessee 37219

TEXAS: John Kinross-Wright, M.D., Commissioner, Department of Mental Health and Mental Retardation, Austin, Texas 78756

UTAH: G. D. Carlyle Thompson, M.D., Director of Health, Division of Health, Department of Health and Welfare, 44 Medical Drive, Salt Lake City, Utah 84113

VERMONT: Jonathan P.A. Leopold, M.D., Commissioner, Department of Mental Health, State Office Building, Montpelier, Vermont 05401

VIRGINIA: Mack I. Shanholtz, M.D., State Health Commissioner, State Department of Health, Richmond, Virginia 32319

VIRGIN ISLANDS: Roy A. Anduze, M.D., Commissioner, Department of Health, P.O. Box 1442, St. Thomas, Virgin Islands 00801

WASHINGTON William Conte, M.D., Director, State Department of Institutions, Olympia, Washington 98501

WEST VIRGINIA: N. H. Dyer, M.D., Director, State Department of Health, Charleston, West Virginia 25311

WISCONSIN: Wilbur J. Schmidt, Secretary, Department of Health and Social Services, 1 West Wilson Street, Madison, Wisconsin 53702

WYOMING: Robert Alberts, M.D., Director, Department of Public Health, State Office Building, Cheyenne, Wyoming 82001

ALLOCATIONS TO STATES

For Construction of Community Facilities for the Mentally Retarded

	1968 1/ Actual	1969 2/ Estimate	1970 Estimate
Totals	$12,000,000	$12,000,000	$8,031,000
Alabama	$ 247,502	$ 247,101	$ 146,091
Alaska	100,000	100,000	100,000
Arizona	100,000	100,000	100,000
Arkansas	139,159	140,465	100,000
California	908,447	916,026	541,573
Colorado	107,804	109,285	100,000
Connecticut	132,759	132,923	100,000
Delaware	100,000	100,000	100,000
District of Columbia	100,000	100,000	100,000
Florida	341,712	343,335	202,987
Georgia	287,876	287,857	170,187
Hawaii	100,000	100,000	100,000
Idaho	100,000	100,000	100,000
Illinois	512,877	513,046	303,324
Indiana	262,416	264,230	156,218
Iowa	148,805	145,193	100,000
Kansas	123,454	123,314	100,000
Kentucky	210,329	207,763	122,834
Louisiana	242,861	243,088	143,718
Maine	100,000	100,000	100,000
Maryland	187,056	189,237	111,881
Massachusetts	264,395	263,504	155,789
Michigan	435,417	440,252	260,286
Minnesota	198,791	197,153	116,561
Mississippi	188,145	185,147	109,463
Missouri	247,788	248,706	147,040
Montana	100,000	100,000	100,000
Nebraska	100,000	100,000	100,000
Nevada	100,000	100,000	100,000
New Hampshire	100,000	100,000	100,000
New Jersey	328,075	330,780	195,564
New Mexico	100,000	100,000	100,000
New York	844,669	834,557	493,407
North Carolina	330,384	329,988	195,095
North Dakota	100,000	100,000	100,000

ALLOCATIONS TO STATES - continues

For Construction of Community Facilities for the Mentally Retarded

	1968 1/ Actual	1969 2/ Estimate	1970 Estimate
Ohio	$ 547,763	$ 549,394	$ 324,813
Oklahoma	148,871	148,469	100,000
Oregon	105,098	105,657	100,000
Pennsylvania	606,647	602,277	356,079
Rhode Island	100,000	100,000	100,000
South Carolina	188,387	188,434	111,406
South Dakota	100,000	100,000	100,000
Tennessee	255,916	254,368	150,387
Texas	654,236	651,236	385,024
Utah	100,000	100,000	100,000
Vermont	100,000	100,000	100,000
Virginia	266,078	266,517	157,570
Washington	156,350	160,332	100,000
West Virginia	118,703	117,421	100,000
Wisconsin	226,221	224,683	132,838
Wyoming	100,000	100,000	100,000
Guam	6,654	7,971	4,713
Puerto Rico	221,943	222,836	131,745
Virgin Islands	4,069	4,915	2,906
American Samoa	2,343	2,540	1,501

NOTE: 1970 allocations are tentative pending receipt of revised population and per capita income data.

1/ 1968 appropriation $18,000,000, less $6,000,000 cost reduction.

2/ 1969 appropriation $6,000,000, plus $6,000,000 from 1968 cost reduction.

APPENDIX A

AUTHORIZATIONS AND APPROPRIATIONS FOR MENTAL RETARDATION CONSTRUCTION PROGRAMS

Fiscal Years 1964-1969

P. L. 88-164, "Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963" as amended
(Millions of Dollars)
Fiscal Years

Construction and Staffing Grants	1964 Authorization	1964 Appropriation	1965 Authorization	1965 Appropriation	1966 Authorization	1966 Appropriation	1967 Authorization	1967 Appropriation	1968 Authorization	1968 Appropriation	1969 Authorization	1969 Appropriation	TOTALS Authorization	TOTALS Appropriation
Research Centers	6.0		8.0	14.0*	6.0	6.0	6.0	6.0					26.0	26.0
Facilities														
University-Affiliated Facilities	5.0	5.0	7.5	7.5	10.0	10.0	10.0	10.0	10.0	.0	20.0	9.1	62.5	41.6
Community Facilities			10.0	10.0	12.5	12.5	15.0	15.0	30.0	12.0	30.0	12.0	97.5	61.5
Staffing									7.0	.0	10.0	8.3	17.0	8.3
Total	11.0	5.0	25.5	31.5	28.5	28.5	31.0	31.0	47.0	12.0	60.0	29.4	203.0	137.4

*Appropriation carried forward from previous fiscal year.

APPENDIX B

NUMBER OF UNIVERSITIES APPROVED FOR CONSTRUCTION OF BOTH A UNIVERSITY-AFFILIATED FACILITY AND A RESEARCH CENTER

Walter E. Fernald State School, Waltham, Massachusetts
University of California, Los Angeles, California
Children's Hospital, Boston, Massachusetts
University of Kansas, Lawrence, Kansas
University of Colorado, Denver, Colorado
University of North Carolina, Chapel Hill, North Carolina
University of Wisconsin, Madison, Wisconsin

SELECTED LAWS RELATING TO MENTAL RETARDATION

38-191 O - 70 - 27

[PUBLIC LAW 88-164, APPROVED OCTOBER 31, 1963, AS AMENDED [1]]

77 Stat. 282

AN ACT To provide assistance in combating mental retardation through grants for construction of research centers and grants for facilities for the mentally retarded and assistance in improving mental health through grants for construction of community mental health centers, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be cited as the "Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963".

Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963

TITLE I [2]—FACILITIES FOR THE MENTALLY RETARDED [3]

SHORT TITLE

SEC. 100. This title may be cited as the "Mental Retardation Facilities Construction Act".

PART A—GRANTS FOR CONSTRUCTION OF CENTERS FOR RESEARCH ON MENTAL RETARDATION AND RELATED ASPECTS OF HUMAN DEVELOPMENT

* * * * *

PART B—PROJECT GRANTS FOR CONSTRUCTION OF UNIVERSITY-AFFILIATED FACILITIES FOR THE MENTALLY RETARDED

AUTHORIZATION OF APPROPRIATIONS

SEC. 121.[4] (a) For the purpose of assisting in the construction (and the planning for the construction) of clinical facilities providing, as nearly as practicable, a full range of inpatient and outpatient services for the mentally retarded (which, for purposes of this part, includes other neurological handicapping conditions found by the

42 U.S.C. 2661

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[1] Provisions of this Act which amended the P.H.S. Act were incorporated as pt. D in title VII, of the P.H.S. Act.

[2] Sec. 2(a) of P.L. 89–10[illegible] amended titles I and IV by changing the words "Title II" wherever they appeared in such titles to read "part A of title II."

[3] The heading of title I amended by sec. 4 of P.L. 90–170.

[4] Sec. 121 amended by secs. 2 (a), (b), and (d)(1) of P.L. 90–170.

Secretary to be sufficiently related to mental retardation to warrant inclusion in this part) and facilities which will aid in demonstrating provision of specialized services for the diagnosis and treatment, education, training, or care of the mentally retarded or in the clinical training of physicians and other specialized personnel needed for research, diagnosis and treatment, education, training, or care of the mentally retarded, including research incidental or related to any of the foregoing activities, there are authorized to be appropriated $5,000,000 for the fiscal year ending June 30, 1964, $7,500,000 for the fiscal year ending June 30, 1965, $10,000,000 each for the fiscal year ending June 30, 1966, the fiscal year ending June 30, 1967, and the fiscal year ending June 30, 1968, and $20,000,000 each for the fiscal year ending June 30, 1969, and the fiscal year ending June 30, 1970. Except as provided in subsection (b), the sums so appropriated shall be used for project grants for construction of public and other nonprofit facilities for the mentally retarded which are associated with a college or university.

(b) [5] (1) Of the sums appropriated pursuant to subsection (a) for any fiscal year, beginning with the fiscal year ending June 30, 1968, an amount equal to 2 per centum thereof (or such smaller amount as the Secretary may determine to be appropriate) shall be available to the Secretary for the purpose of making grants to cover not to exceed 75 per centum of the costs of the planning of projects with respect to the construction of which applications for grants may be made under this part. Not more than $25,000 shall be granted under this subsection with respect to any project.

(2) Planning grants under this subsection shall be made by the Secretary to such applicants and upon such terms and conditions as he shall by regulations prescribe. Payment of grants under this subsection shall be made in advance or by way of reimbursement, as the Secretary may determine.

(3) Whenever, in the succeeding provisions of this part, the term "grant", "grants", or "funds" is employed, such term shall be deemed not to include any grant under this subsection or any of the funds of any such grant.

APPLICATIONS

42 U.S.C. 2662 SEC. 122. Applications for grants under this part with respect to any facility may be approved by the Secretary only if the application contains or is supported by reasonable assurances that—

(1) the facility will be associated, to the extent prescribed in regulations of the Secretary, with a college or university hospital (including affiliated hospitals), or with such other part of a college or

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[5] Subsec. 121(b) added by sec. 2(c) of P.L. 90–170.

university as the Secretary may find appropriate in the light of the purposes of this part;

(2) the plans and specifications are in accord with regulations prescribed by the Secretary under section 133(3);

(3) title to the site for the project is or will be vested in one or more of the agencies or institutions filing the application or in a public or other nonprofit agency or institution which is to operate the facility;

(4) adequate financial support will be available for construction of the project and for its maintenance and operation when completed; and

(5) all laborers and mechanics employed by contractors or subcontractors in the performance of
work on construction of the project will be paid 49 Stat. 1011
wages at rates not less than those prevailing on similar construction in the locality as determined by the Secretary of Labor in accordance with the
Davis-Bacon Act, as amended (40 U.S.C. 276a— 63 Stat. 108
276a–5); and the Secretary of Labor shall have with
respect to the labor standards specified in this para- 64 Stat. 1267
graph the authority and functions set forth in Reorganization Plan Numbered 14 of 1950 (15 F.R. 3176; 5 U.S.C. 133z-15) and section 2 of the Act of June 13, 1934, as amended (40 U.S.C. 276c).

AMOUNT OF GRANTS; PAYMENTS

Sec. 123. (a) The total of the grants with respect to 42 U.S.C. 2663
any project for the construction of a facility under this part may not exceed 75 per centum of the necessary cost of construction thereof as determined by the Secretary.

(b) Payments of grants under this part shall be made in advance or by way of reimbursement, in such installments consistent with construction progress, and on such conditions as the Secretary may determine.

RECOVERY

Sec. 124. If any facility with respect to which funds have been paid under this part shall, at any time within twenty years after the completion of construction—

(1) be sold or transferred to any person, agency, 42 U.S.C. 2664
or organization which is not qualified to file an application under this part, or

(2) cease to be a public or other nonprofit facility for the mentally retarded, unless the Secretary determines, in accordance with regulations, that there is good cause for releasing the applicant or other owner from the obligation to continue such facility as a public or other nonprofit facility for the mentally retarded,

the United States shall be entitled to recover from either the transferor or the transferee (or, in the case of a facility which has ceased to be a public or other nonprofit facility for the mentally retarded, from the owners thereof) an amount bearing the same ratio to the then value (as determined by the agreement of the parties or by action brought in the district court of the United States for the district in which the facility is situated) of so much of the facility as constituted an approved project or projects, as the amount of the Federal participation bore to the cost of the construction of such project or projects.

NONDUPLICATION OF GRANTS

58 Stat. 682
42 U.S.C. 201 note

SEC. 125.[6] No grant may be made after January 1, 1964, under any provision of the Public Health Service Act, for any of the fiscal years in the period beginning July 1, 1963, and ending June 30, 1970, for construction of any facility for the mentally retarded described in this part, unless the Secretary determines that funds are not available under this part to make a grant for the construction of such facility.

42 U.S.C. 2665

PART C—GRANTS FOR CONSTRUCTION OF FACILITIES FOR THE MENTALLY RETARDED

AUTHORIZATION OF APPROPRIATIONS

42 U.S.C. 2671

SEC. 131.[6] There are authorized to be appropriated, for grants for construction of public and other nonprofit facilities for the mentally retarded, $10,000,000 for the fiscal year ending June 30, 1965, $12,500,000 for the fiscal year ending June 30, 1966, $15,000,000 for the fiscal year ending June 30, 1967, $30,000,000 each for the fiscal year ending June 30, 1968, and the fiscal year ending June 30, 1969, and $50,000,000 for the fiscal year ending June 30, 1970.

ALLOTMENTS TO STATES

42 U.S.C. 2672

SEC. 132. (a) For each fiscal year, the Secretary shall, in accordance with regulations, make allotments from the sums appropriated under section 131 to the several States on the basis of (1) the population, (2) the extent of the need for facilities for the mentally retarded, and (3) the financial need of the respective States; except that no such allotment to any State, other than the Virgin Islands, American Samoa, and Guam, for any fiscal year may be less than $100,000. Sums so allotted to a State for a fiscal year for construction and remaining unobligated at the end of such year shall remain available to such State for such purpose for the next fiscal year (and for such year only), in addition to the sums allotted, to such State for such next fiscal year.

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[6] Secs. 125 and 131 amended by secs. 2(c) and 3(a), respectively, of P.L. 90–170.

(b) In accordance with regulations of the Secretary, any State may file with him a request that a specified portion of its allotment under this part be added to the allotment of another State under this part for the purpose of meeting a portion of the Federal share of the cost of a project for the construction of a facility for the mentally retarded in such other State. If it is found by the Secretary that construction of the facility with respect to which the request is made would meet needs of the State making the request and that use of the specified portion of such State's allotment, as requested by it, would assist in carrying out the purposes of this part, such portion of such State's allotment shall be added to the allotment of the other State under this part, to be used for the purpose referred to above.

(c) Upon the request of any State that a specified portion of its allotment under this part be added to the allotment of such State under part A of title II, and upon (1) the simultaneous certification to the Secretary by the State agency designated as provided in the State plan approved under this part to the effect that it has afforded a reasonable opportunity to make applications for the portion so specified and there have been no approvable applications for such portion, or (2) a showing satisfactory to the Secretary that the need for the community mental health centers in such State is substantially greater than for the facilities for the mentally retarded, the Secretary shall, subject to such limitations as he may by regulations prescribe, promptly adjust the allotments of such State in accordance with such request and shall notify such State agency and the State agency designated under the State plan approved under part A of title II, and thereafter the allotments as so adjusted shall be deemed the State's allotments for purposes of this part and part A of title II.

(d) [7] (1) At the request of any State, a portion of any allotment or allotments of such State under this part shall be available to pay one-half (or such smaller share as the State may request) of the expenditures found necessary by the Secretary for the proper and efficient administration during such year of the State plan approved under this part; except that not more than 2 per centum of the total of the allotments of such State for a year, or $50,000, whichever is less, shall be available for such purpose for such year. Payments of amounts due under this paragraph may be made in advance or by way of reimbursement, and in such installments, as the Secretary may determine.

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[7] Subsec. 132(d) added by sec. 3(c) of P.L. 90–170.

(2) Any amount paid under paragraph (1) to any State for any fiscal year shall be paid on condition that there shall be expended from State sources for such year for administration of the State plan approved under this part not less than the total amount expended for such purposes from such sources during the fiscal year ending June 30, 1967.

REGULATIONS

Sec. 133. Within six months after enactment of this Act, the Secretary shall, after consultation with the Federal Hospital Council (established by section 633 of the Public Health Service Act and hereinafter in this part referred to as the "Council"), by general regulations applicable uniformly to all the States, prescribe—

(1) the kinds of services needed to provide adequate services for mentally retarded persons residing in a State;

(2) the general manner in which the State agency (designated as provided in the State plan approved under this part) shall determine the priority of projects based on the relative need of different areas, giving special consideration to facilities which will provide comprehensive services for a particular community or communities;

(3) general standards of construction and equipment for facilities of different classes and in different types of location; and

(4) that the State plan shall provide for adequate facilities for the mentally retarded for persons residing in the State, and shall provide for adequate facilities for the mentally retarded to furnish needed services for persons unable to pay therefor. Such regulations may require that before approval of any application for a facility or addition to a facility is recommended by a State agency, assurance shall be received by the State from the applicant that there will be made available in such facility or addition a reasonable volume of services to persons unable to pay therefor, but an exception shall be made if such a requirement is not feasible from a financial viewpoint.

STATE PLANS

Sec. 134. (a) After such regulations have been issued, any State desiring to take advantage of this part shall submit a State plan for carrying out its purposes. Such State plan must—

(1) designate a single State agency as the sole agency for the administration of the plan, or designate such agency as the sole agency for supervising the administration of the plan;

(2) contain satisfactory evidence that the State agency designated in accordance with paragraph (1) hereof will have authority to carry out such plan in conformity with this part;

(3) provide for the designation of a State advisory council which shall include representatives of State agencies concerned with planning, operation, or utilization of facilities for the mentally retarded and of nongovernment organizations or groups concerned with education, employment, rehabilitation, welfare, and health, and including representatives of consumers of the services provided by such facilities;

(4) set forth a program for construction of facilities for the mentally retarded (A) which is based on a statewide inventory of existing facilities and survey of need; (B) which conforms with the regulations prescribed under section 133(1); and (C) which meets the requirements for furnishing needed services to persons unable to pay therefor, included in regulations prescribed under section 133(4);

(5) set forth the relative need, determined in accordance with the regulations prescribed under section 133(2), for the several projects included in such programs, and provide for the construction, insofar as financial resources available therefor and for maintenance and operation make possible, in the order of such relative need;

(6) provide such methods of administration of the State plan, including methods relating to the establishment and maintenance of personnel standards on a merit basis (except that the Secretary shall exercise no authority with respect to the selection, tenure of office, or compensation of any individual employed in accordance with such methods), as are found by the Secretary to be necessary for the proper and efficient operation of the plan;

(7)[8] provide minimum standards (to be fixed in the discretion of the State) for the maintenance and operation of facilities which receive Federal aid under this part and, effective July 1, 1969, provide for enforcement of such standards with respect to projects approved by the Secretary under this part after June 30, 1967;

(8) provide for affording to every applicant for a construction project an opportunity for hearing before the State agency;

(9) provide that the State agency will make such reports in such form and containing such information as the Secretary may from time to time reasonably require, and will keep such records and afford

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[8] Par. (7) of sec. 134 amended by sec. 5 of P.L. 90-170.

such access thereto as the Secretary may find necessary to assure the correctness and vertification of such reports; and

(10) provide that the State agency will from time to time, but not less often than annually, review its State plan and submit to the Secretary any modifications thereof which it considers necessary.

(b) The Secretary shall approve any State plan and any modification thereof which complies with the provisions of subsection (a). The Secretary shall not finally disapprove a State plan except after reasonable notice and opportunity for a hearing to the State.

APPROVAL OF PROJECTS

SEC. 135. (a) For each project for construction pursuant to a State plan approved under this part, there shall be submitted to the Secretary through the State agency an application by the State or a political subdivision thereof or by a public or other nonprofit agency. If two or more such agencies join in the construction of the project, the application may be filed by one or more of such agencies. Such application shall set forth—

(1) a description of the site for such project;

(2) plans and specifications therefor in accordance with the regulations perscribed by the Secretary under section 133(3);

(3) reasonable assurance that title to such site is or will be vested in one or more of the agencies filing the application or in a public or other nonprofit agency which is to operate the facility;

(4) reasonable assurance that adequate financial support will be available for the construction of the project and for its maintenance and operation when completed;

(5) reasonable assurance that all laborers and mechanics employed by contractors or subcontractors in the performance of work on construction of the project will be paid wages at rates not less than those prevailing on similar construction in the locality as determined by the Secretary of Labor in accordance with the Davis-Bacon Act, as amended (40 U.S.C. 276a—276a-5); and the Secretary of Labor shall have with respect to the labor standards specified in this paragraph the authority and functions set forth in Reorganization Plan Numbered 14 of 1950 (15 F.R. 3176; 5 U.S.C. 133z-15) and section 2 of the Act of June 13, 1934, as amended (40 U.S.C. 276c); and

(6) a certification by the State agency of the Federal share for the project.

The Secretary shall approve such application if sufficient funds to pay the Federal share of the cost of construction of such project are available from the allotment to the State, and if the Secretary finds (A) that the application contains such reasonable assurance as to title, financial support, and payment of prevailing rates of wages and overtime pay; (B) that the plans and specifications are in accord with the regulations prescribed pursuant to section 133; (C) that the application is in conformity with the State plan approved under section 134 and contains an assurance that in the operation of the facility there will be compliance with the applicable requirements of the State plan and of the reuglations prescribed under section 133(4) for furnishing needed facilities for persons unable to pay therefor, and with State standards for operation and maintenance; and (D) that the application has been approved and recommended by the State agency and is entitled to priority over other projects within the State in accordance with the regulations prescribed pursuant to section 133(2). No application shall be disapproved by the Secretary until he has afforded the State agency an opportunity for a hearing.

(b) Amendment of any approved application shall be subject to approval in the same manner as an original application.

WITHHOLDING OF PAYMENTS

SEC. 136. Whenever the Secretary after reasonable notice and opportunity for hearing to the State agency designated as provided in section 134(a)(1), finds—

(1) that the State agency is not complying substantially with the provisions required by section 134 to be included in its State plan or with regulations under this part;

(2) that any assurance required to be given in an application filed under section 135 is not being or cannot be carried out;

(3) that there is a substantial failure to carry out plans and specifications approved by the Secretary under section 135; or

(4) that adequate State funds are not being provided annually for the direct administration of the State plan,

the Secretary may forthwith notify the State agency that—

(5) no further payments will be made to the State from allotments under this part; or

(6) no further payments will be made from allotments under this part for any project or projects designated by the Secretary as being affected by the action or inaction referred to in paragraph (1), (2), (3), or (4) of this section,

as the Secretary may determine to be appropriate under the circumstances; and, except with regard to any project for which the application has already been approved and which is not directly affected, further payments from such allotments may be withheld, in whole or in part, until there is no longer any failure to comply (or to carry out the assurance or plans and specifications or to provide adequate State funds, as the case may be) or, if such compliance (or other action) is impossible, until the State repays or arranges for the repayment of Federal moneys to which the recipient was not entitled.

NONDUPLICATION OF GRANTS

SEC. 137.[9] No grant may be made after January 1, 1964, under any provision of the Public Health Service Act, for any of the fiscal years in the period beginning July 1, 1964, and ending June 30, 1970, for construction of any facility for the mentally retarded described in this part, unless the Secretary determines that funds are not available under this part to make a grant for the construction of such facility.

PART D[10]—GRANTS FOR THE COST OF PROFESSIONAL AND TECHNICAL PERSONNEL OF COMMUNITY MENTAL RETARDATION FACILITIES

AUTHORIZATION OF GRANTS

SEC. 141. (a) For the purpose of assisting in the establishment and initial operation of facilities for the mentally retarded providing all or part of a program of comprehensive services for the mentally retarded principally designed to serve the needs of the particular community or communities in or near which the facility is situated, the Secretary may, in accordance with the provisions of this part, make grants to meet, for the temporary periods specified in this section, a portion of the costs (determined pursuant to regulations under section 144) of compensation of professional and technical personnel for the initial operation of new facilities for the mentally retarded or of new servies in facilities for the mentally retarded.

(b) Grants for such costs for any facility for the mentally retarded under this part may be made only for the period beginning with the first day of the first month for which such a grant is made and ending with the close of four years and three months after such first day; and such grants with respect to any such facility may not exceed 75 per centum of such costs for the period ending with the close of the fifteenth month following such first day, 60 per centum of such costs for the first year thereafter, 45 per centum of such costs for the second year thereafter, and 30 per centum of such costs for the third year thereafter.

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[9] Sec. 137 amended by sec. 3(b) of P.L. 90-170.
[10] Pt. D added by sec. 4 of P.L. 90-170.

(c) In making such grants, the Secretary shall take into account the relative needs of the several States for services for the mentally retarded, their relative financial needs, and their populations.

Sec. 142 (a) Grants under this part with respect to any facility for the mentlly retarded may be made only upon application, and only if—

(1) the applicant is a public or nonprofit private agency or organization which owns or operates the facility;

(2) (A) a grant was made under part C of this title to assist in financing the construction of the facility or (B) the type of service to be provided as part of such program with the aid of a grant under this part was not previously being provided by the facility with respect to which such application is made;

(3) the Secretary determines that there is satisfactory assurance that Federal funds made available under this part for any period will be so used as to supplement and, to the extent practical, increase the level of State, local, and other non-Federal funds for mental retardation services that would in the absence of such Federal funds be made available for (or under) the program described in paragraph (2) of this subsection, and will in no event supplant such State, local, and other non-Federal funds; and

(4) in the case of an applicant in a State which has in existence a State plan relating to the provision of services for the mentally retarded, the services to be provided by the facility are consistent with the plan.

(b) No grant may be made under this part after June 30, 1972, with respect to any facility for the mentally retarded or with respect to any type of service provided by such a facility unless a grant with respect thereto was made under this part prior to July 1, 1970.

PAYMENTS

Sec. 143. Payment of grants under this part may be made (after necessary adjustment on account of previously made overpayments or underpayments) in advance or by way of reimbursement, and on such terms and conditions and in such installments, as the Secretary may determine.

REGULATIONS

SEC. 144. The Secretary shall prescribe general regulations concerning the eligibility of facilities under this part, determination of eligible costs with respect to which grants may be made, and the terms and conditions (including those specified in section 142) for approving applications under this part.

AUTHORIZATION OF APPROPRIATIONS

SEC. 145. There are authorized to be appropriated $7,000,000 for the fiscal year ending June 30, 1968, $10,000,000 for the fiscal year ending June 30, 1969, and $14,000,000 for the fiscal year ending June 30, 1970, to enable the Secretary to make initial grants to facilities for the mentally retarded under the provisions of this part. For the fiscal year ending June 30, 1969, and each of the next five years, there are authorized to be appropriated such sums as may be necessary to make grants to such facilities which have previously received a grant under this part and are eligible for such a grant for the year for which sums are being appropriated under this sentence.

* * * * *

TITLE IV—GENERAL

DEFINITIONS

SEC. 401. For purposes of this Act— **42 U.S.C. 2691**

(a) The term "State" includes Puerto Rico, Guam, American Samoa, the Virgin Islands, and the District of Columbia.

(b) The term "facility for the mentally retarded" means a facility specially designed for the diagnosis, treatment, education, training, or custodial care of the mentally retarded, including facilities for training specialists and sheltered workshops for the mentally retarded, but only if such workshops are part of facilities which provide or will provide comprehensive services for the mentally retarded.

(c) The term "community mental health center" means a facility providing services for the prevention or diagnosis of mental illness, or care and treatment of mentally ill patients, or rehabilitation of such persons, which services are provided principally for persons residing in a particular community or communities in or near which the facility is situated.

(d) The terms "nonprofit facility for the mentally retarded", "nonprofit community mental health center", and "nonprofit private institution of higher learning" mean, respectively, a facility for the mentally retarded, a community mental health center, and an institution of higher learning which is owned and operated by one or more nonprofit corporations or associations no part of the net earnings of which inures, or may lawfully inure, to the benefit of any private shareholder or individual; and the term "nonprofit private agency or organization" means an agency or organization which is such a corporation or association or which is owned and operated by one or more of such corporations or associations.

(e)[24] The term "construction" includes construction of new buildings, acquisition, expansion, remodeling, and alteration of existing buildings, and initial equipment of any such buildings (including medical transportation facilities); including architect's fees, but excluding the cost of off-site improvements and the cost of the acquisition of land.

(f) The term "cost of construction" means the amount found by the Secretary to be necessary for the construction of a project.

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[24] Sec. 401(e) amended by sec. 4(b) of P.L. 90–31.

(g) The term "title", when used with reference to a site for a project, means a fee simple, or such other estate or interest (including a leasehold on which the rental does not exceed 4 per centum of the value of the land) as the Secretary finds sufficient to assure for a period of not less than fifty years undisturbed use and possession for the purposes of construction and operation of the project.

(h) The term "Federal share" with respect to any project means—

(1) if the State plan under which application for such project is filed contains, as of the date of approval of the project application, standards approved by the Secretary pursuant to section 402 the amount determined in accordance with such standards by the State agency designated under such plan; or

(2) if the State plan does not contain such standards, the amount (not less than 33½ per centum and not more than either 66⅔ per centum or the State's Federal percentage, whichever is the lower) established by such State agency for all projects in the State: *Provided*, That prior to the approval of the first such project in the State during any fiscal year such State agency shall give to the Secretary written notification of the Federal share established under this paragraph for such projects in such State to be approved by the Secretary during such fiscal year, and the Federal share for such projects in such State approved during such fiscal year shall not be changed after such approval.

(i) The Federal percentage for any State shall be 100 per centum less that percentage which bears the same ratio to 50 per centum as the per capita income of such State bears to the per capita income of the United States, except that the Federal percentage for Puerto Rico, Guam, American Samoa, and the Virgin Islands shall be 66⅔ per centum.

(j) (1) The Federal percentages shall be promulgated by the Secretary between July 1 and August 31 of each even-numbered year, on the basis of the average of the per capita incomes of the States and of the United States for the three most recent consecutive years for which satisfactory data are available from the Department of Commerce. Such promulgation shall be conclusive for each of the two fiscal years in the period beginning July 1 next succeeding such promulgation; except that the Secretary shall promulgate such percentages as soon as possible after the enactment of this Act, which promulgation shall be conclusive for the fiscal year ending June 30, 1965.

(2) The term "United States" means (but only for purposes of this subsection and subsection (i)) the fifty States and the District of Columbia.

(k) The term "Secretary" means the Secretary of Health, Education, and Welfare.

STATE STANDARDS FOR VARIABLE FEDERAL SHARE

SEC. 402. The State plan approved under part C of title I or title II may include standards for determination of the Federal share of the cost of projects approved in the State under such part or title, as the case may be. Such standards shall provide equitably (and, to the extent practicable, on the basis of objective criteria) for variations between projects or classes of projects on the basis of the economic status of areas and other relevant factors. No such standards shall provide for a Federal share of more than 66⅔ per centum or less than 33⅓ per centum of the cost of construction of any project. The Secretary shall approve any such standards and any modifications thereof which comply with the provisions of this section. 42 U.S.C. 2692

PAYMENTS FOR CONSTRUCTION

SEC. 403. (a) Upon certification to the Secretary by the State agency, designated as provided in section 134 in the case of a facility for the mentally retarded, or section 204 in the case of a community mental health center, based upon inspection by it, that work has been performed upon a project, or purchases have been made, in accordance with the approved plans and specifications, and that payment of an installment is due to the applicant, such installment shall be paid to the State, from the applicable allotment of such State, except that (1) if the State is not authorized by law to make payments to the applicant, the payment shall be made directly to the applicant, (2) if the Secretary, after investigation or otherwise, has reason to believe that any act (or failure to act) has occurred requiring action pursuant to section 136 or section 206, as the case may be, payment may, after he has given the State agency so designated notice of opportunity for hearing pursuant to such section, be withheld, in whole or in part, pending corrective action or action based on such hearing, and (3) the total of payments under this subsection with respect to such project may not exceed an amount equal to the Federal share of the cost of construction of such project. 42 U.S.C. 2693

(b) In case an amendment to an approved application is approved as provided in section 135 or 205 or the estimated cost of a project is revised upward, any additional payment with respect thereto may be made from the applicable allotment of the State for the fiscal year in which such amendment or revision is approved.

* * * * *

JUDICIAL REVIEW

42 U.S.C. 2694

72 Stat. 941

Sec. 404. If the Secretary refuses to approve any application for a project submitted under section 135 or 205, the State agency through which such application was submitted, or if any State is dissatisfied with his action under section 134(b) or 204(b) or section 136 or 206, such State, may appeal to the United States court of appeals for the circuit in which such State is located, by filing a petition with such court within sixty days after such action. A copy of the petition shall be forthwith transmitted by the clerk of the court to the Secretary, or any officer designated by him for that purpose. The Secretary thereupon shall file in the court the record of the proceedings on which he based his action, as provided in section 2112 of title 28, United States Code. Upon the filing of such petition, the court shall have jurisdiction to affirm the action of the Secretary or to set it aside, in whole or in part, temporarily or permanently, but until the filing of the record, the Secretary may modify or set aside his order. The findings of the Secretary as to the facts, if supported by substantial evidence, shall be conclusive, but the court, for good cause shown, may remand the case to the Secretary to take further evidence, and the Secretary may thereupon make new or modified findings of fact and may modify his previous action, and shall file in the court the record of the further proceedings. Such new or modified findings of fact shall likewise be conclusive if supported by substantial evidence. The judgment of the court affirming or setting aside, in whole or in part, any action of the Secretary shall be final, subject to review by the Supreme Court of the United States upon certiorari or certification as provided in section 1254 of title 28, United States Code. The commencement of proceedings under this section shall not, unless so specifically ordered by the court, operate as a stay of the Secretary's action. 62 Stat. 928

RECOVERY

SEC. 405. If any facility or center with respect to which funds have been paid under section 403 shall, at any time within twenty years after the completion of construction— 42 U.S.C. 2695

(1) be sold or transferred to any person, agency, or organization (A) which is not qualified to file an application under section 135 or 205, or (B) which is not approved as a transferee by the State agency designated pursuant to section 134 (in the case of a facility for the mentally retarded) or section 204 (in case of a community mental health center), or its successor; or

(2) cease to be a public or other nonprofit facility for the mentally retarded or community mental health center, as the case may be, unless the Secretary determines, in accordance with regulations, that there is good cause for releasing the applicant or other owner from the obligation to continue such facility as a public or other nonprofit facility for the mentally retarded or such center as a community mental health center,

the United States shall be entitled to recover from either the transferor or the transferee (or, in the case of a facility or center which has ceased to be public or other nonprofit facility for the mentally retarded or community mental health center, from the owners thereof) an amount bearing the same ratio to the then value (as determined by the agreement of the parties or by action brought in the district court of the United States for the district in which the center is situated) of so much of such facility or center as constituted an approved project or projects, as the amount of the Federal participation bore to the cost of the construction of such project or projects. Such right of recovery shall not constitute a lien upon such facility or center prior to judgment.

STATE CONTROL OF OPERATIONS

SEC. 406. Except as otherwise specifically provided, nothing in this Act shall be construed as conferring on any Federal officer or employee the right to exercise any supervision or control over the administration, personnel, maintenance, or operation of any facility for the mentally retarded or community mental health center with respect to which any funds have been or may be expended under this Act. 42 U.S.C. 2696

* * * * *

RECORDS AND AUDIT

SEC. 408.[26] (a) Each recipient of assistance under this Act shall keep such records as the Secretary shall prescribe, including records which fully disclose the amount and disposition by such recipient of the proceeds of such assistance, the total cost of the project or undertaking in connection with which such assistance is given or used, and the amount of that portion of the cost of the project or undertaking supplied by other sources, and such other records as will facilitate an effective audit.

(b) The Secretary and the Comptroller General of the United States, or any of their duly authorized representatives, shall have access for the purpose of audit and examination to any books, documents, papers, and records of the recipients that are pertinent to the assistance received under this Act.

NONDUPLICATION

SEC. 409.[27] In determining the amount of any grant under this Act for the costs of any project there shall be excluded from such costs an amount equal to the sum of (1) the amount of any other Federal grant which the applicant has obtained, or is assured of obtaining, with respect to such project, and (2) the amount of any non-Federal funds required to be expended as a condition of such other Federal grant.

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[26] Sec. 408 added by sec. 3 of P.L. 89-105.

[27] Sec. 409 added by sec. 304 of P.L. 90-574.

Prepared Statement of Larry L. Campbell, Coordinator of Special Education for Isabella Intermediate School District Special Education Division, Mt. Pleasant, Mich.

December 1, 1969.

Re "Developmental Disabilities Services and Facilities Construction Act of 1969" (S. 2846)

Labor and Public Welfare Committee, Health Subcommittee

Mr. Chairman, I appreciate this opportunity to express support for S. 2846. If placed into law, this bill will improve education for handicapped individuals in the State of Michigan.

As Coordinator of Special Education for the Isabella Intermediate School District, Mt. Pleasant, Michigan, I must wear many hats. To be more specific, a coordinator must survey needs, tabulate and analyze the needs, and recommend services to meet the needs of handicapped individuals. He must also assist local districts in the establishment and coordination of these services. The professional and moral obligations of coordinators become heavy loads once needs and priorities are established. If monies for facilities and programs are not available or if trained professionals to staff programs are not to be found, the load becomes even greater. Please let me make one point clear, I am not complaining about my position, I only wish to convey to the committee that as a coordinator many more recommendations are made than can be carried out.

Please let me narrow the scope of this problem at hand. There are 63 intermediate school districts in Michigan. The office of the Isabella County Intermediate School District is located in Mt. Pleasant. Isabella County has a population of approximately 36,000 people of which about 15,000 reside in Mt. Pleasant. The intermediate school district is comprised of three constituent school districts, Mt. Pleasant Public Schools, Shepherd Public Schools, and Beal City Public Schools.

The Isabella Intermediate School District acts as an administrative unit that functions between the Michigan State Department of Education and the local school systems. The intermediate district can provide service to handicapped children in local districts which are unable to provide such services due to low population or lack of adequate financing.

The 1969–70 school population for the Isabella Itermediate School District stands at 8,271. Of this number, 676 handicapped students are being served by 25 special educators in one or more special programs. 676 students may appear to be a large percentage of our school population and yet there are waiting lists for many programs. Additional programs are needed in the areas of diagnosis, school social work, emotional disturbance, learning disabilities, perceptual development and physical handicaps. The more knowledge we gain from our 12 programs for the mentally handicapped, the more we realize these programs or classes are not, in themselves, adequate in meeting the needs of handicapped individuals. Thus, waiting lists grow, parents wonder where their tax dollars are going, and administrators struggle daily with—"am I meeting the needs of children in which I have been entrusted?"

I don't feel this situation is unique to our rural setting. There certainly may be similar conditions in hundreds of other communities, rural and urban. The point is that if this country is to progress as it has in the past, handicapped individuals must be equipped, through some form of education, to function in a computer world. They must have the opportunity to work to their capacity, to be productive individuals, and have self-respect.

This concept is by no means new and/or innovative in nature but is realistic if legislation, both federal and state, permit changes of approach to education and method of financial support for programs for the handicapped.

Recent research would indicate that we as special educators have reached a point where we should be *practicing* instead of *preaching*. I feel we know a lot more about the handicapped individual than we lead the public to believe. Communities, however, are handicapped to the extent that adequate financial support is lacking prohibiting the establishment of comprehensive programs for the handicapped. There are many excellent programs in Michigan. There are also areas where only basic educational needs are being met. I can speak for my colleagues when I say that meeting the basic needs of handicapped individuals just isn't adequate.

The recently established C. L. Hoogerland Memorial Workshop by Isabella and Gratiot Counties is excellent testimony that handicapped individuals need additonal service after public school programs. If time permits, please read the enclosed brochure explaining the functions of the sheltered workshop. The services are limited again by lack of trained professionals and adequate financial support.

Research again would substantiate the fact that early intervention is essential if some handicaps are to be successfully remediated. Yet there are no programs for pre-school multihandicapped children in my country. In September a group of local parents in Mt. Pleasant pooled their monies and started their own program. These parents wanted their children to have a chance. They are going to give them an opportunity to learn to function as citizens in a complex society.

I realize my district is very small, however, I feel our problems are unique and should be represented. The picture I "paint" is not all dark. We are providing those services we are capable of providing under present rules and regulations and financial means. S. 2846 would provide new impetus to research we now have at hand concerning early intervention, remediation, and follow-up of development disabilities.

I confess that I have not spoke directly to S. 2846 but rather have disclosed needs in Isabella County that S. 2846 could help alleviate if put into law. I have tried, to the best of my ability, to point out some serious problems that exist. These problems can be changed to successes if states and local communities have the necessary legislation to meet these problems. Handicapped individuals have proven that if given a chance to learn and to an opportunity, can be happy productive citizens. I feel this is the charge of every individual, handicapped or not.

Again I wish to take this opportunity to thank the Health Subcommittee for affording me their time and consideration. I would also ask that serious consideration be granted for the passage of S. 2846 and other related bills that attempt to make this and future generations better in every respect.

THE UNIVERSITY OF MICHIGAN,
INSTITUTE FOR THE STUDY OF MENTAL RETARDATION,
Ann Arbor, Mich., November 13, 1969.

Hon. EDWARD M. KENNEDY,
U.S. Senate, 431 Old Senate Office Building,
Washington, D.C.

DEAR SENATOR KENNEDY: I very much appreciated the opportunity to testify before the Subcommittee on Health of the Senate Labor and Public Welfare Committee on S. 2846.

I was distressed by the testimony of the administration witnesses and saw nothing in what they presented that would alleviate the problems which exist in the field. This was especially evident in terms of their very general statement on the manpower needs, and their lack of strong support of the University-Affiliated Center concept as one of the most viable and promising approaches to generate the needed manpower.

While I briefly described in my testimony the development of our University-Affiliated Center here, I am enclosing a brochure which describes the program in some greater detail. Perhaps this might be of some interest or value to you.

Again my thanks for the opportunity to testify before your committee.

Cordially,

JULIUS S. COHEN, *Associate Director*

Enclosure.

THE INSTITUTE FOR THE STUDY OF MENTAL RETARDATION

ISMR

THE UNIVERSITY OF MICHIGAN · ANN ARBOR, MICHIGAN

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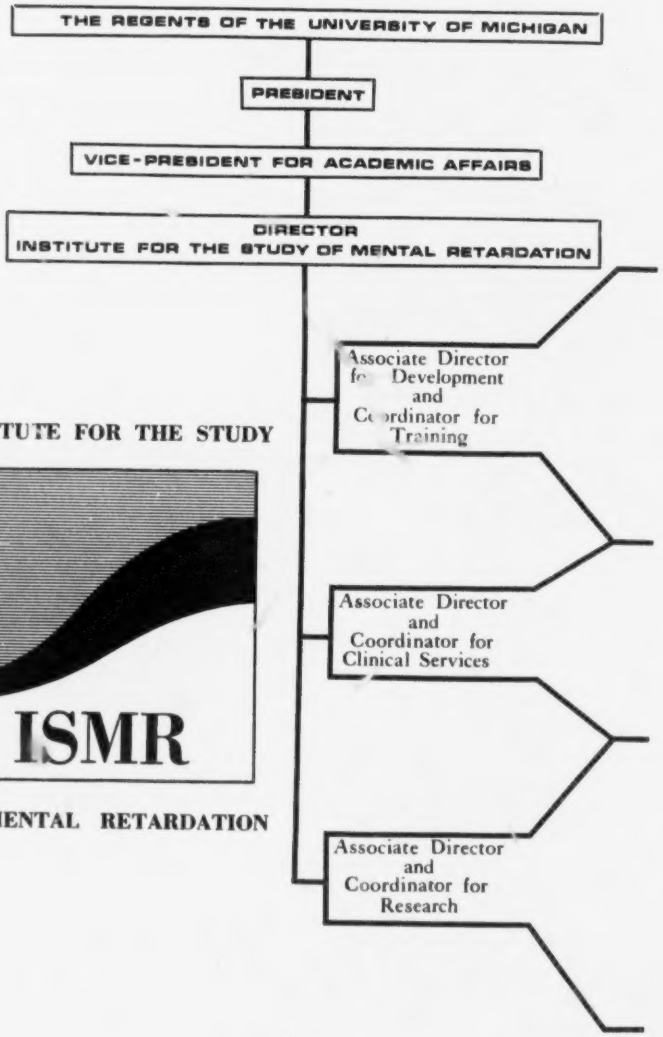
INSTITUTE FOR THE STUDY

General Structure


THE REGENTS OF THE UNIVERSITY OF MICHIGAN
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INSTITUTE FOR THE STUDY

ISMR

OF MENTAL RETARDATION

OF MENTAL RETARDATION

General Overview

The Institute for the Study of Mental Retardation is the outgrowth of recommendations from a two-year faculty and administration committee appointed in 1963 to assess The University of Michigan's role in meeting the problems of mental retardation. The Institute was established by The Regents of The University of Michigan in June, 1966. The Institute will be instrumental in fostering interdisciplinary training of all fields concerned with mental retardation and related health problems. It will achieve this primary goal through a program consisting of 1) ***manpower training and development***, 2) ***exemplary clinical services***, and 3) ***research and evaluation***.

The acute shortage of trained personnel in mental retardation has led the Institute to place its primary emphasis on ***manpower training and development***. This phase of activities is concerned with a ***preservice education program*** that trains professional and non-professional staff members of the various facilities; with a ***continuing education program*** that keeps the staff up to date with the current concepts of mental retardation; with an ***adult education program*** that informs parents, volunteers, community leaders, and employers about mental retardation; and with a ***materials development program*** that devises materials about retardation to be used in training programs for personnel as well as materials for use with retarded individuals.

The highly specialized services which are required in diagnosing, evaluating, treating, educating, training, and caring for the mentally retarded are an integral part of the training role assumed by the Institute and are being developed. Another equally important aspect of the Institute is the ***cooperative development of field settings*** in which primary consideration is given to the agency's and community's ability to support the program. This will enable such programs to be replicated in other areas through local funding and fiscal structures.

The research programs of the Institute, both disciplinary and interdisciplinary, will be directed at ***uncovering the causes*** of mental retardation; at ***developing a more meaningful taxonomy*** of the different syndromes of mental retardation; and at ***elucidating the basic biological and behavioral processes*** characterizing these syndromes. In addition, the research thrust will be aimed at evaluating how best to apply and disseminate this knowledge to the care, rehabilitation, and education of the mentally retarded. As part of the research effort, an evaluation program will also be carried out to asses and improve the Institute's operations. This program will attempt to ***increase the cost effectiveness*** of the Institute's operations, ***maintain a balance*** among the Institute's programs and resources, and ***develop evaluation models*** for the Institute and other organizations.

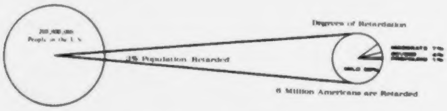
ISMR AND THE BROAD VIEW OF MENTAL RETARDATION

The definition of mental retardation used by the American Association on Mental Deficiency ("Mental retardation refers to a significant sub-average intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior") is the Institute's starting point. Also included as part of the Institute's concerns are the issues of related neurological involvement and problems of the multiply handicapped where mental retardation is associated with visual and auditory impairment, prematurity and congenital malformations, cerebral palsy, epilepsy, neuropsychiatric disturbances, speech disabilities, or any other physical disabilities. Finally, components related to psychological problems and social or environmental deprivation are also within the Institute's scope of its concept of mental retardation. Programming in this area will provide services for high risk children from disadvantaged environments and will include individuals from this background. Programs will be designed to help train students to work effectively with these populations and to evaluate the effectiveness of various service patterns.

THE INCIDENCE OF MENTAL RETARDATION

Scope Of The Retardation Problem In The U.S.

—retardation afflicts nearly *6 million* Americans
—retardations afflicts *10 times* as many persons as *diabetes*
—retardation afflicts *20 times* as many persons as *T.B.*
—retardation afflicts *600 times* as many persons as *polio*
—*One family in 5* is affected
—*126,000 children* are born *every year* (one every 5 minutes) who will be diagnosed as retarded



To meet the needs of some of these people, ISMR will establish service models including an Experimental Study and Training Unit, a Demonstration School Unit, and a Cooperative Clinical Service Unit. These units will train personnel while providing care and treatment for retardates in need of the services of the Institute. Since it is apparent that the present system employed in the United States neither fully meets the needs of the retarded nor provides sufficient manpower for this purpose, the Institute will attack both of these areas.

Traditional Estimates Of 3% Are Probably Low Because They Generally Do Not Include Such Factors As:

Cultural Deprivation
Physical Disabilities
Neurological Impairments

ISMR PROGRAMS are focused primarily on the young, but will be involved with programming at all age levels. The overall emphasis will be on developing, for teaching purposes, interlocking patterns of services to meet the life-long needs of retardates. Training and service models will be established in southeastern Michigan, but should have direct application to programs throughout the state. The Institute will work with community agencies anywhere in the state to develop interdisciplinary services for retarded children designed to serve as models for replication elsewhere and based on realistic tax and fiscal programs of the local communities.

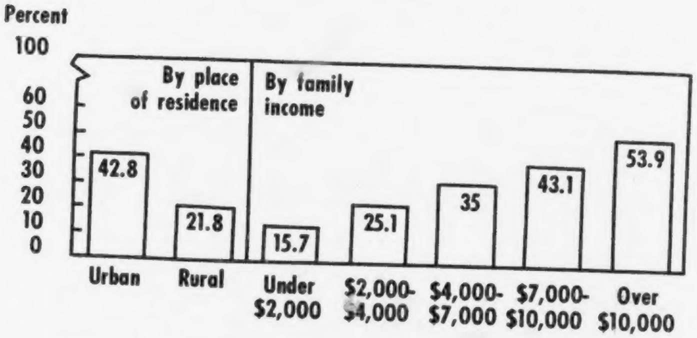
Retardation And Cultural Deprivation

—Lack of Health Care

—Children of low income groups have fewer *routine physical exams;* therefore, handicapping conditions may go undetected.

—As reported by the President's Committee on Mental Retardation in M.R. '68, *The Edge of Change,* the number of routine physical examinations are directly related to a family's income level:

Children Under Age 17 Who Had At Least One Routine Physical Examination During A 12-Month Period, 1962–63



—45% of all women who have babies in public hospitals receive no *prenatal care.*

—The *infant mortality* rate in low income groups is nearly double that of other income groups.

—A child from a low income or rural area is *15 times as likely to be* ***mentally retarded*** as a child from a higher income family.

—75% of the nation's mentally retarded are found in *urban and rural slums.*

—Lack of Intellectual Achievement

—*Selective Service System rejection rates* for intellectual underachievement are 23% overall and 60% among some low income groups.

—3 times as many low income children *fail in school* as children from other income groups.

ISMR WILL STUDY AND COMBAT RETARDATION LINKED WITH PHYSICAL DISABILITIES AND NEUROLOGICAL IMPAIRMENTS

Retardation And Physical Disabilities

- —Approximately 3 million American children are physically handicapped; many of them are intellectually retarded as well. For example:
  - —approximately 75% of all children with cerebral palsy are, to some degree, retarded in their intellectual development.
  - —approximately 88% of athetoid cerebral palsy children, and 50% of all hemiplegics, have perceptual disturbances which affect learning and intellectual development.
  - —approximately 30% of blind children are, to some degree, intellectually retarded.

Retardation And Neurological Impairments

- —10% of live births are premature. Of these, approximately 50% will have serious sensory, mental, and/or motor disabilities which will impair school learning.
- —Slightly more than 7% of newborn children are found to be neurologically damaged or defective by the 4th week after birth.
- —Approximately 12–15% of 12-month old babies are found or suspected to be neurologically deviant.
- —Slightly more than 8% of babies at 12 months of age have audiomotor disabilities. The majority of these do not have hearing losses.
- —Communication specialists with Operation Head Start have observed serious language and speech retardation in children served by this program.

ISMR, in conjunction with the schols and colleges of The University of Michigan and county and state health facilities, will implement programs and services to achieve specific patient-centered goals. These objectives may be achieved through one or several of the following disciplines:

Administration
Audiology
Child Psychiatry
Dentistry
Epidemiology
Law
Maternal and Child Health
Nursing
Nutrition
Occupational Therapy
Pediatric Neurology
Pediatrics
Physical Medicine
Physical Therapy
Psychology
Recreational Therapy
Rehabilitation Counseling
Social Work
Special Education
Speech and Language Pathology

ISMR AND THE STATE OF MICHIGAN PLAN

The Institute is closely related to the state of Michigan plan to combat mental retardation. This plan for action includes the following areas:

- —**Manpower Training and Development**
- —**Prevention And Diagnosis**
- —**Education And Training**
- —**Vocational Rehabilitation**
- —**Social Services**
- —**Residential Care**
- —**Research Development**
- —**Implementation**

The plans for the Institute for the Study of Mental Retardation include all of these areas, but especially:

—Manpower Training And Development

- —*Pre-service training* for the professional and non-professional working with the mentally retarded
- —*Continuing education* to update knowledge of specialists and general practitioners
- —*Adult education* for parents, volunteers, community leaders, and employers
- —*Materials development* for training programs in universities and other agencies

—Services

- —Consultation in planning, developing, and operating *exemplary services* throughout the state
- —Development of *model services* in selected communities
- —Provision of specialized *diagnostic services*

—Research

- —*Basic*, to expand understanding of the etiology and nature of mental retardation
- —*Applied*, to assess and improve services to the retarded
- —*Evaluation* of all aspects of Institute programming

SERVICES TO THE MENTALLY RETARDED IN MICHIGAN

Community Programs

- **Diagnostic And Evaluation**
- **Public And Private School**
- **Day Care**
- **Social Service**
- **Referral**
- **Recreation**
- **Rehabilitation**

95% of retardates live in the community.

in 1967–68 in Michigan, there were:

41 training centers serving	1,023
2182 type A, B, C classes serving	34,269
70 sheltered workshops serving	1,347
in 1966–67 there were:	
10 state residential programs serving	12,592
17 private residential programs serving	564
Total Served	**49,475**

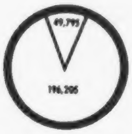
Residential Programs

- **Treatment**
- **Half-Way Houses**
- **Non-Residential Service**
- **Care And Custody**
- **Support for Community And Family Programming**

But

based on a 3% incidence rate, there were 246,000 retardates in Michigan in 1965, of whom only 49,795 (20%) were being served by residential and community services. This leaves *196,205 (80%) unserved* by any of these programs.

49,895 Are Served by the Above
Community and Residential Programs:



BUT this leaves 196,205, or 80%, of the Retardates
in Michigan UNSERVED by any of these programs

In addition, the 3% incidence rate may be too low since it does not include the

- —15% of all children who are socially disadvantaged
- —12–15% of all children who are neurologically deviant or suspect
- —many physically handicapped children who show retardation associated with their physical disability

The lack of trained personnel in all fields related to mental retardation prevents filling existing positions, much less new ones. Therefore, ISMR will concentrate its efforts on **Manpower Training And Development.**

ISMR WILL TRY TO MEET THE PRIMARY PROBLEM–MANPOWER

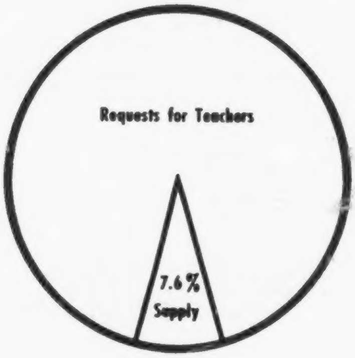
The number one obstacle to meeting the needs of the mentally retarded is the lack of trained personnel. For example, in teaching:

School Programs For The Mentally Handicapped In Michigan

	Type A	Type B	Type C
Students	24,791	287	1,762
Teachers	1,502	20	73

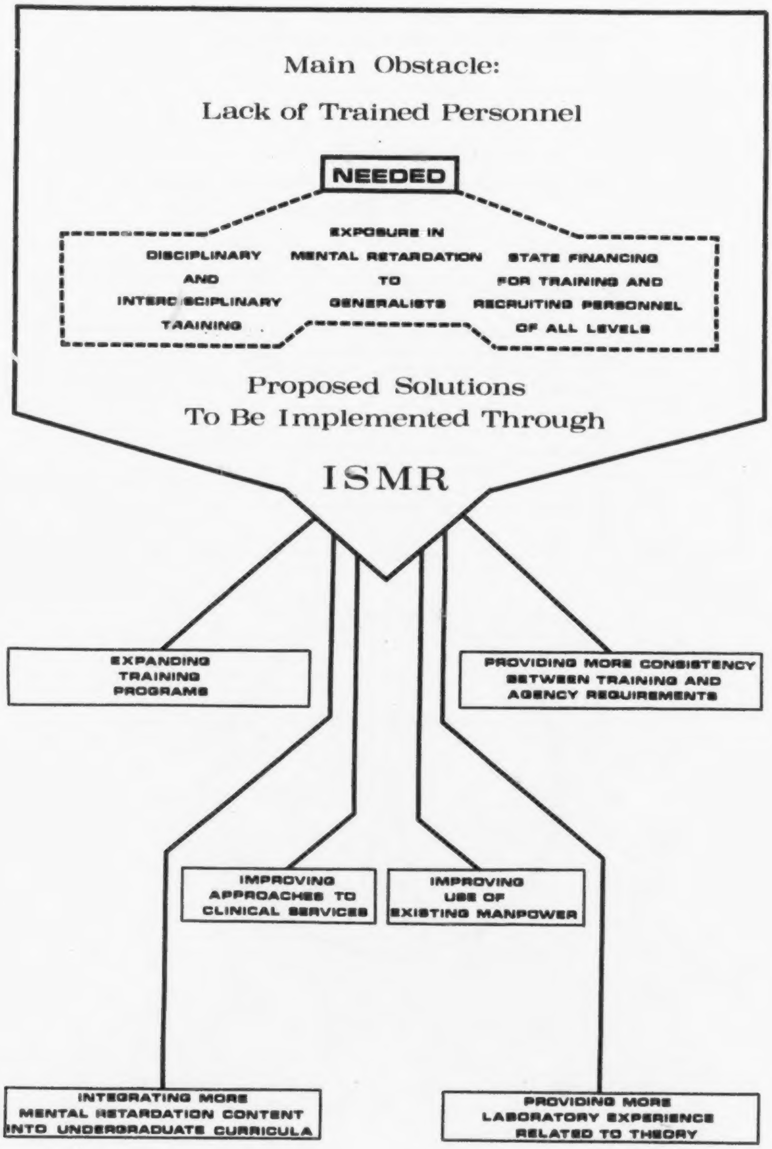
The need underlined by the 1966 legislative survey of special education problems was for manpower training. The survey concludes that in special education, the number one obstacle was lack of trained personnel. To meet 1975 needs, the state will have to produce approximately *2,400* new teachers, assuming the present number of teachers remain on their jobs. Consequently, there is a need for approximately *4,000* teachers by 1975, if the present pupil-teacher ratio of 15 to 1 is maintained.

These figures do not include the approximately 40,000 additional students not served by these programs, but who will definitely need them by 1975.



Only 7.6% of the state's requests for teachers of the mentally retarded can be met by available candidates.

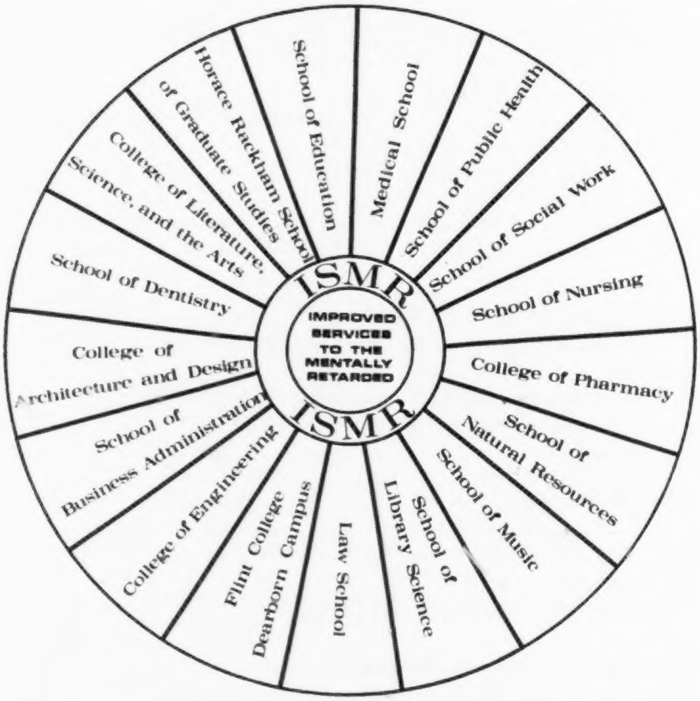
Teaching is only one of the many areas in Mental Retardation faced with serious manpower shortages. The Institute will develop training programs in over twenty areas.


Main Obstacle:
Lack of Trained Personnel
NEEDED
DISCIPLINARY AND INTERDISCIPLINARY TRAINING
EXPOSURE IN MENTAL RETARDATION TO GENERALISTS
STATE FINANCING FOR TRAINING AND RECRUITING PERSONNEL OF ALL LEVELS
Proposed Solutions
To Be Implemented Through
ISMR
EXPANDING TRAINING PROGRAMS
PROVIDING MORE CONSISTENCY BETWEEN TRAINING AND AGENCY REQUIREMENTS
IMPROVING APPROACHES TO CLINICAL SERVICES
IMPROVING USE OF EXISTING MANPOWER
INTEGRATING MORE MENTAL RETARDATION CONTENT INTO UNDERGRADUATE CURRICULA
PROVIDING MORE LABORATORY EXPERIENCE RELATED TO THEORY

INSTITUTE FOR THE STUDY OF MENTAL RETARDATION

The Institute for the Study of Mental Retardation, established by the Regents of The University of Michigan in June, 1966, is responsible directly to the Vice-President for Academic Affairs as an independent unit within the University. The Institute fosters interdisciplinary *training* in all disciplines concerned with mental retardation and related health problems, so that it is able to take advantage of all the resources The University of Michigan has to offer. This primary goal is to be achieved in part through a program of exemplary *manpower training and development*, *clinical services*, and *research*.

PROGRAMMATIC RELATIONSHIPS FOR TRAINING


School of Education
Medical School
School of Public Health
School of Social Work
School of Nursing
College of Pharmacy
School of Natural Resources
School of Music
School of Library Science
Law School
Flint College Dearborn Campus
College of Engineering
School of Business Administration
College of Architecture and Design
School of Dentistry
College of Literature, Science, and the Arts
Horace Rackham School of Graduate Studies
ISMR
IMPROVED SERVICES TO THE MENTALLY RETARDED
ISMR

ISMR and Schools and Colleges of The University of Michigan

THE ISMR MANPOWER DEVELOPMENT PROGRAM

The acute shortage of trained personnel at all levels in the field of mental retardation has led the Institute to place its main emphasis on training. More trained people are needed, and more training per person is essential if specialized services are to be effective.

Pre-Service Education Program

Specialized Training—

- —for graduate students specializing in mental retardation
- —for those who do not go beyond their baccalaureate degree

General Exposure to Mental Retardation—

- —to all students in professional training programs
- —to undergraduate students to sensitize them to mental retardation and career opportunities in this field

Training of Non-Professionals

- —working with community colleges, ISMR will cooperate in training non-professionals as:
  - —aides, attendants, orderlies
  - —assistants in professional areas
  - —members in combined professional and non-professional programs

Continuing Education Program

Short and long-term training for professional and non-professional practitioners—

- —to update the concepts of specialists in mental retardation
- —to present current concepts of mental retardation to general practitioners

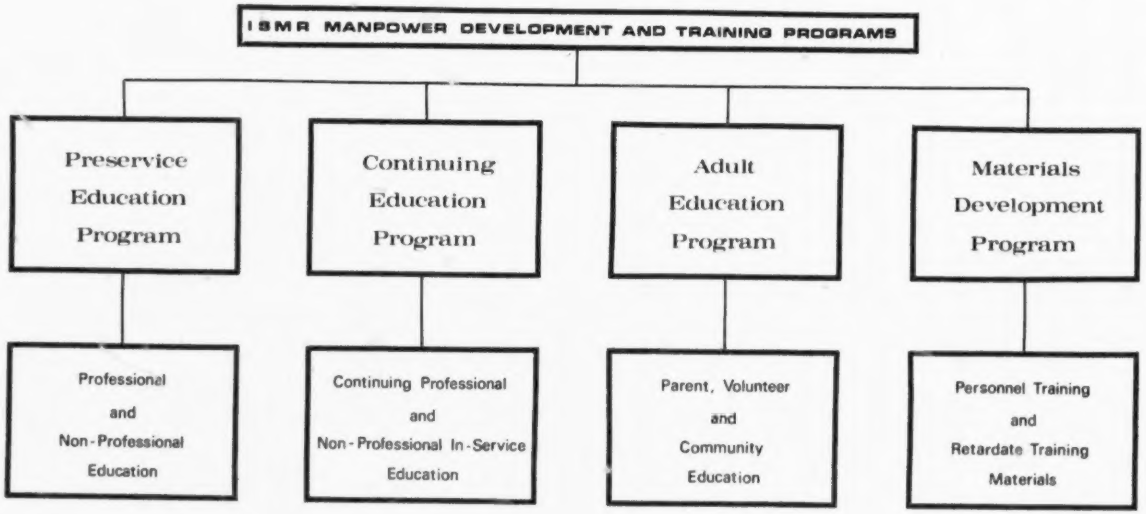
Adult Education Program

- —training volunteers
- —introducing concepts of mental retardation to the community-at-large
- —introducing concepts of mental retardation to employers

Materials Development Program

- —developing materials to be used in training programs
- —developing materials to be used with retardates
- —making materials available to other agenices and universities in the state

ISMR -- Training Program Relationships


ISMR MANPOWER DEVELOPMENT AND TRAINING PROGRAMS
Preservice Education Program
Continuing Education Program
Adult Education Program
Materials Development Program
Professional and Non-Professional Education
Continuing Professional and Non-Professional In-Service Education
Parent, Volunteer and Community Education
Personnel Training and Retardate Training Materials

THE ISMR CLINICAL SERVICE PROGRAM

The Clinical Service Program is characterized by a concern for the individual as a unique whole with the goal of understanding and helping him as well as his parents. Within the Institute, all services to retarded individuals and their families are defined as Clinical Services.

Demonstration Schools Unit

- —to develop and demonstrate innovative approaches to special education
- —to operate cooperatively with community schools focusing on education and managing retarded children in group settings

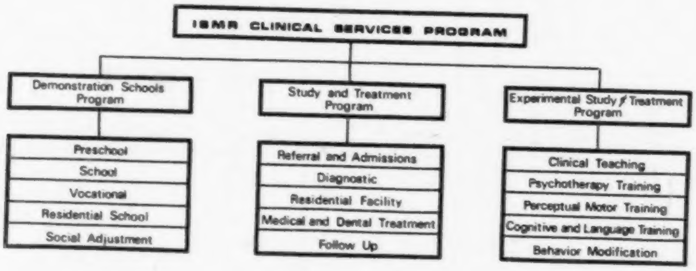
Study And Treatment Unit

- —to develop and demonstrate patterns of service, staffing, and quality control within an interdisciplinary environment
- —to insure maximum visibility for the Institute for the Study of Mental Retardation and the disciplines represented on the core staff

Experimental Study And Treatment Unit

- —to provide optimum conditions to meet professional training goals
- —to serve the retarded population
- —to act as a basic setting for research on new pedagogical approaches, social-psychological research, and other cooperative interdisciplinary investigation and intervention techniques

ISMR -- Clinical Services Program Relationships

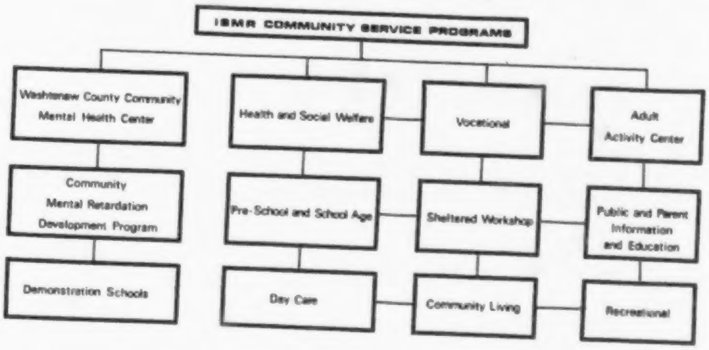

ISMR CLINICAL SERVICES PROGRAM
Demonstration Schools Program
Study and Treatment Program
Experimental Study & Treatment Program
Preschool
School
Vocational
Residential School
Social Adjustment
Referral and Admissions
Diagnostic
Residential Facility
Medical and Dental Treatment
Follow Up
Clinical Teaching
Psychotherapy Training
Perceptual Motor Training
Cognitive and Language Training
Behavior Modification

THE ISMR COMMUNITY SERVICE PROGRAMS

ISMR will

- —provide intensive diagnostic and evaluation services
- —work with existing community service programs to provide services for the mentally retarded
- —develop service models to assist communities throughout the state in creating or strengthening services
- —provide continuous consultative assistance to service agencies
- —establish working relationships with residential treatment programs, such as:
    - —Washtenaw County Community Health Center
    - —Plymouth State Home and Training School
    - —Washtenaw County Health Department
    - —Maternal and Infant Project, Detroit
    - —Washtenaw County Public Schools, Special Education
    - —Community Day Care Centers
    - —Washtenaw County Adult Activity Center
    - —Sheltered Workshops
    - —Private Social Service Agencies
    - —State and Local Welfare Agencies

ISMR -- Community Services Program Relationships


ISMR COMMUNITY SERVICE PROGRAMS
Washtenaw County Community Mental Health Center
Health and Social Welfare
Vocational
Adult Activity Center
Community Mental Retardation Development Program
Pre-School and School Age
Sheltered Workshop
Public and Parent Information and Education
Demonstration Schools
Day Care
Community Living
Recreational

ISMR–RESEARCH IN MENTAL RETARDATION PROGRAM

Research at the Institute will be directed at:

—uncovering the causes of mental retardation
—developing a more meaningful taxonomy of the different syndromes of mental retardation
—elucidating the basic biological and behavioral processes characterizing these syndromes
—applying this knowledge to the care, rehabilitation, and education of the mentally retarded

Research Units Within ISMR

Individual Faculty Research

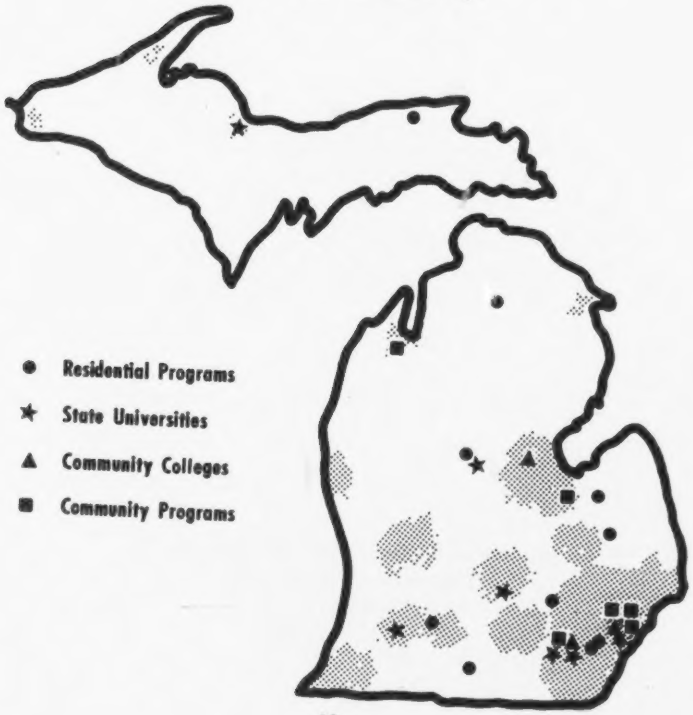
- Epidemiology
  - Etiology
  - Patterns of Service
  - Quality of Service
  - Follow-up
- Research Laboratories
- Evaluation
  - Systems Analysis of Projected Goals
  - Sociological Evaluation of the Team Process
- Resources and Materials
  - Resource Center and Library
  - Materials Evaluation and Dissemination Center
- Legal Research
  - Institute of Continuing Legal Education
- Agency Research
  - Standards
  - Patterns of Service
  - Manpower Training
  - Manpower Utilization

ISMR COORDINATES WITH STATE EFFORTS TO COMBAT MENTAL RETARDATION

Institute programs are designed to be a part of the Michigan state plan to combat mental retardation. To maintain this relationship, the Institute has:

—established an Institute-State Advisory Committee
—obtained representation on the Southeastern Regional Interagency Committee
—initiated cooperative efforts with other state universities
—developed close cooperation with the residential treatment programs
—established liaison with a number of community service programs
—initiated cooperative planning with community college training programs

State Wide Relationships


● Residential Programs
★ State Universities
▲ Community Colleges
■ Community Programs

ISMR ADMINISTRATIVE STAFF

William M. Cruickshank, Ph.D., Director
Julius S. Cohen, Ed.D., Associate Director for Development
and Coordinator for Training
Arthur W. Fleming, M.D., Associate Director and Coordinator
for Clinical Services
Norman L. Thoburn, Ed.M., Assistant to the Director

Institute for the Study of Mental Retardation
The University of Michigan
611 Church Street
Ann Arbor, Michigan
MCMLXIX

APPENDIX

STATEMENT OF SENATOR JACOB K. JAVITS ON INTRODUCING S. 3277, THE MENTAL RETARDATION SERVICES AMENDMENTS OF 1969

Mr. JAVITS. Mr. President, I introduce, for the administration, the Mental Retardation Services Amendments of 1969. The bill assures the continuing support of the Federal Government in providing services and expanded facilities for the mentally retarded, including special incentives to encourage these activities in areas having the most critical need.

Included among the activities for which grants could be made under the bill are the provision of services for the mentally retarded—operation grants—construction of mental retardation facilities, development and demonstration of new or improved techniques for provision of services for the mentally retarded; training of personnel to work on the various problems of the mentally retarded; and State and local planning, administration, and technical assistance.

I am pleased that the administration bill provides:

First, the maximum on the Federal share, of the costs of new projects, including construction projects, shall be 75 percent except in poverty areas where 90 percent would be permitted;

Second, the duration of support for projects providing mental retardation services is to be extended from the present 51 months to 8 years except for poverty areas where support could be granted for 10 years; and

Third, the Federal share of support for projects providing services would decline gradually, from a maximum of 75 percent in the first 2 years to 10 percent in the 8th year, and in poverty areas from 90 percent in the first 2 years to 10 percent in the 10th year.

Other major features of the bill provide that operational support would continue to be provided to recipients who have already received commitments for future support under the existing law; Federal funds for all types of mental retardation projects in a State would not be less than the amounts allotted to the State in fiscal year 1970 for construction of community mental retardation facilities; joint funding arrangements with other Federal programs could be entered into; and before grants are made, States must be given an opportunity to review and make recommendations on projects in their jurisdictions.

In order to meet the problem to which the President called attention in his message of April 30, 1969, to the Congress on improving the administration of Federal programs, the Department of Health, Education, and Welfare has provided in the bill for consolidating the present separate categories of grants for construction of mental retardation facilities, for construction of university affiliated facilities, and for initial staffing of community mental retardation facilities into a single, flexible program of grants to public or nonprofit agencies covering facilities and services for the mentally retarded.

Appropriations authorizations are requested for 3 years.

(The next of the bill S. 3277 follows.)

91st CONGRESS
1st Session

S. 3277

IN THE SENATE OF THE UNITED STATES

December 20, 1969

Mr. Javits introduced the following bill; which was read twice and referred to the Committee on Labor and Public Welfare

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A BILL

To amend the Mental Retardation Facilities Construction Act to extend and improve the provisions thereof, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be cited as the "Mental Retardation Services Amendments of 1969".

Sec. 2. Effective with respect to appropriations for fiscal years beginning after June 30, 1970, title I of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 is amended to read as follows:

II

"TITLE I—GRANTS FOR SERVICES AND FOR CONSTRUCTION AND OPERATION OF FACILITIES FOR THE MENTALLY RETARDED

"SHORT TITLE

"SEC. 100. This title may be cited as the 'Mental Retardation Services Act'.

"AUTHORIZATION OF APPROPRIATIONS

"SEC. 101. There are authorized to be appropriated for grants under this title such sums as may be necessary for the fiscal year ending June 30, 1971, and for each of the next two fiscal years. For the fiscal year ending June 30, 1972, and each of the ten succeeding fiscal years, there are authorized to be appropriated such sums as may be necessary to make grants for projects which have received a grant under this title from funds appropriated under the preceding sentence, and are eligible for such a grant for the year for which such sums are being appropriated under this sentence.

"AUTHORIZATION OF GRANTS

"SEC. 102. (a) Of the sums appropriated pursuant to section 101 for a fiscal year, such amount as the Secretary determines to be necessary shall be available for grants with respect to facilities which received, prior to July 1, 1970, grants under part D of this title as in effect prior to such date, and which would have been eligible for such grants in the same amounts under such part for such year had such part remained in effect.

"(b) The remainder of the sums so appropriated for such year shall be available for grants by the Secretary to public or nonprofit private agencies and organizations for up to 75 per centum of the cost (except as provided in subsections (c) and (e)) of projects for—

"(1) provision of services for the mentally retarded, including costs of operation, staffing, and maintenance of facilities for the mentally retarded;

"(2) State or local planning, administration, or technical assistance relating to services and facilities for the mentally retarded;

"(3) training of physicians and other specialized personnel needed for research, diagnosis, treatment, education, rehabilitation, training, or care of the mentally retarded;

"(4) developing or demonstrating new or improved techniques for provision of diagnosis, treatment, education, rehabilitation, training, care, or other services for the mentally retarded; and

"(5) construction of facilities for the mentally retarded, including facilities for any of the foregoing.

"(c) In the case of any project which is to be constructed, or to provide services for persons, in an area designated by the Secretary as an urban or rural poverty area, including planning and technical assistance in connection therewith, the Federal portion of the cost thereof which may be met by a grant under this title may not exceed 90 per centum of such cost.

"(d) Payment of grants under this section may be made in advance or by way of reimbursement, and in such installments and on such conditions, as the Secretary may determine.

"(e) No grant for any project to provide services to the mentally retarded may be made under the provisions of this title for a period in excess of eight years, or in the case of any area designated by the Secretary as an urban or rural poverty area, for any period in excess of ten years. Grants with respect to the costs of any such project may not exceed—

"(1) except as provided in clause (2), 75 per centum of such costs for the first two years after the first day of the first month for which such a grant is made with respect to such project, 60 per centum of such costs for the third year after such first day, 50 per centum of such costs for the fourth year after such first day, 40 per centum of such costs for the fifth year after such first day, 30 per centum of such costs for the sixth year after such first day, 20 per centum of such costs for the seventh year after such first day, and 10 per centum of such costs for the eighth year after such first day; or

"(2) in the case of any such project providing services for persons in an area designated by the Secretary as an urban or rural poverty area, 90 per centum of such costs for the first two years after the first day of the first month for which such a grant is made with respect to such project, 80 per centum of such costs for the third year after such first day, 70 per centum of such costs for the fourth year after such first day, 60 per centum of such costs for the fifth year after such first day, 50 per centum of such costs for the sixth year after such first day, 40 per centum of such costs for the seventh year after such first day, 30 per centum of such costs for the eighth year after such first day, 20 per centum of such costs for the ninth year after such first day, and 10 per centum of such costs for the tenth year after such first day.

"TOTAL OF FEDERAL PAYMENTS IN A STATE

"SEC. 103. The total of grants under this title for all projects in a State for any fiscal year beginning after June 30, 1970, shall not be less than the allotment to such State for the fiscal year ending June 30, 1970, under section 132 as in effect prior to July 1, 1970, as computed prior to the application of subsections (b), (c), and (d) thereof, except to the extent that the Secretary determines that the total cost of approvable applications for projects in such State for such year will be less than such allotment.

"REGULATIONS

"SEC. 104. The Secretary shall prescribe general regulations concerning the eligibility of projects, determination of eligible costs with respect to which grants may be made, general standards of construction and equipment for various types of facilities of different classes and in different types of locations, and the terms and conditions for approving applications under this title.

"APPROVAL OF APPLICATIONS

"SEC. 105. The Secretary shall not approve any application for a grant under this title unless he determines that—

"(1) the Governor (or, in the case of the Trust Territory of the Pacific Islands, the High Commissioner) of the State in which the project is to be located, or any agency or official of the State designated by the Governor or Commissioner, has been afforded an opportunity to review and make recommendations with respect to the project;

"(2) in the case of an application for a project in a State which has in existence a State mental retardation construction plan, or comprehensive plan relating to services for the mentally retarded, which has been reviewed by the State agency designated or established pursuant to section 314 (a) (2) (A) of the Public Health Service and by any other State agency determined by the Governor to be appropriate, the project is consistent with such plan or, if the State has both, with both such plans;

"(3) there is reasonable assurance that the funds paid with respect to the project under this title for any period will be so used as to supplement and, to the extent practicable, to increase the level of State, local, and other non-Federal funds for mental retardation services which, in the absence of such Federal funds, would otherwise be available for mental retardation projects in such State and will in no event supplant such State, local, or non-Federal funds; and

"(4) if the grant is for construction of a facility, there is reasonable assurance that (A) for not less than twenty years after completion of construction, the facility will be used for the purposes for which it was constructed, (B) adequate financial support will be available for the construction of the facility and for its maintenance and operation when completed, and (C) all laborers and mechanics employed by contractors or subcontractors in the performance of work on construction of the facility will be paid wages at rates not less than those determined by the Secretary of Labor in accordance with the Davis-Bacon Act, as amended (40 U.S.C. 276a–276a–5); and the Secretary of Labor shall have with respect to the labor standards specified in this clause the authority and functions set forth in Reorganization Plan Numbered 14 of 1950 (15 F.R. 3176; 5 U.S.C. 913) and section 2 of the Act of June 13, 1934, as amended (40 U.S.C. 276c).

"PROGRAM EVALUATION

"SEC. 106. Such portion of any appropriation under this title for any fiscal year ending after June 30, 1970, as the Secretary may determine, but not exceeding 1 per centum thereof, shall be available to the Secretary for evaluation (directly or by grants or contracts) of the program authorized by this title.

"JOINT FUNDING

"SEC. 107. Pursuant to regulations prescribed by the Secretary, where funds are advanced for a single project by more than one Federal agency to an agency or organization assisted under this title, any one Federal agency may be designated to act for all in administering the funds advanced. In such cases, a single non-Federal share requirement may be established according to the proportion of funds advanced by each Federal agency, and any such agency may waive any technical grant or contract requirement (as defined by such regulations) which is inconsistent with the similar requirements of the administering agency or which the administering agency does not impose.

"NONDUPLICATION OF GRANTS

"SEC. 108. No grant may be made after January 1, 1964, under any provision of the Public Health Service Act, for any of the fiscal years in the period beginning July 1, 1963, and ending June 30, 1973, for construction of any facility for the mentally retarded described in this title, unless the Secretary determines that funds are not available under this title to make a grant for the construction of such facility.

"RECOVERY

"SEC. 109. If any facility with respect to which funds have been paid under this title shall, at any time within twenty years after the completion of construction—

"(1) be sold or transferred to any person, agency, or organization which is not qualified to file an application under this title, or

"(2) cease to be a public or other nonprofit facility of the type referred to in section 102 (b) (5), unless the Secretary determines, in accordance with regulations, that there is good cause for releasing the applicant or other owner from the obligation to continue such facility as such a public or other nonprofit facility,

the United States shall be entitled to recover from either the transferor or the transferee (or, in the case of a facility to which clause (2) applies, from the owner thereof) an amount bearing the same ratio to the then value (as determined by agreement of the parties or by action brought in the district court of the United States for the district in which the facility is situated) of so much of the facility as constituted an approved project or projects, as the amount of the Federal participation bore to the cost of the construction of such project or projects."

AMENDMENTS TO GENERAL PROVISIONS

Trust Territory of the Pacific Islands Included in Definition of State

SEC. 3. (a) Effective with respect to grants under title I of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 made from funds appropriated for fiscal years beginning after June 30, 1970, paragraph (a) of section 401 thereof (42 U.S.C. 2691) is amended by inserting "the Trust Territory of the Pacific Islands," after "the Virgin Islands,".

Facilities for the Mentally Retarded

(b) Effective with respect to projects approved under title I of such Act for fiscal years beginning after June 30, 1970, paragraph (b) of section 401 is amended to read:

"(b) The term 'facility for the mentally retarded' means a facility specially designed for the diagnosis, treatment, education, training, or personal care of the mentally retarded, including facilities for training specialists, group living accommodations for the mentally retarded, and sheltered workshops for the mentally retarded, but only, in the case of such sheltered workshops, if they are part of facilities which provide or will provide comprehensive services for the mentally retarded."

Cost of Land Included in Cost of Construction

(c) Effective with respect to projects approved under title I of such Act for fiscal years beginning after June 30, 1970, so much of paragraph (e) of such section 401 as follows the semicolon is amended to read "including architect's fees and the cost of the acquisition of land, but excluding the cost of off-site improvements."

State Standards for Variable Federal Share

(d) Effective with respect to projects approved under title I of such Act for fiscal years beginning after June 30, 1970, section 402 of such Act (42 U.S.C. 2692) is amended by striking out "part C of title I or", and by striking out "part or" in the first sentence thereof.

Payments for Construction

(e) Effective with respect to payments for construction under title I of such Act from appropriations for fiscal years beginning after June 30, 1970, subsection (a) of section 403 of such Act is amended by striking out "section 134 in the case of a facility for the mentally retarded, or", and by striking out in clause (2) "section 136 or". Subsection (b) of such section is amended by striking out "section 135 or".

Judicial Review

(f) (1) Section 404 of such Act is amended by striking out "135 or", "134 (b) or", and "136 or" in the first sentence thereof.

(2) The amendment made by paragraph (1) shall not be effective with respect to applications submitted under section 135 of such Act as in effect prior to the enactment of this section, or appeals with respect to action under section 134 (b) or 136 of such Act as in effect prior to such enactment.

Recovery

(g) Effective with respect to construction projects for which funds are paid out of appropriations for any fiscal year beginning after June 30, 1970, paragraph (1) of section 405 of such Act is amended by striking out "135 or" in clause (A), and by striking out "section 134 (in the case of a facility for the mentally retarded or" in clause (B) thereof.

Senator KENNEDY. The subcommittee stands adjourned.

(Whereupon, at 4:40 p.m., the subcommittee was adjourned, to reconvene subject to the call of the Chair.)

○